

Rebelling with Care.

Exploring
open technologies
for commoning
healthcare



An abstract graphic on the left side of the page. It features a background of vertical black lines on a light greenish-grey textured surface. A black wavy line runs vertically through the center. A red hatched area, composed of diagonal lines, is located in the bottom left corner, partially overlapping the vertical lines.

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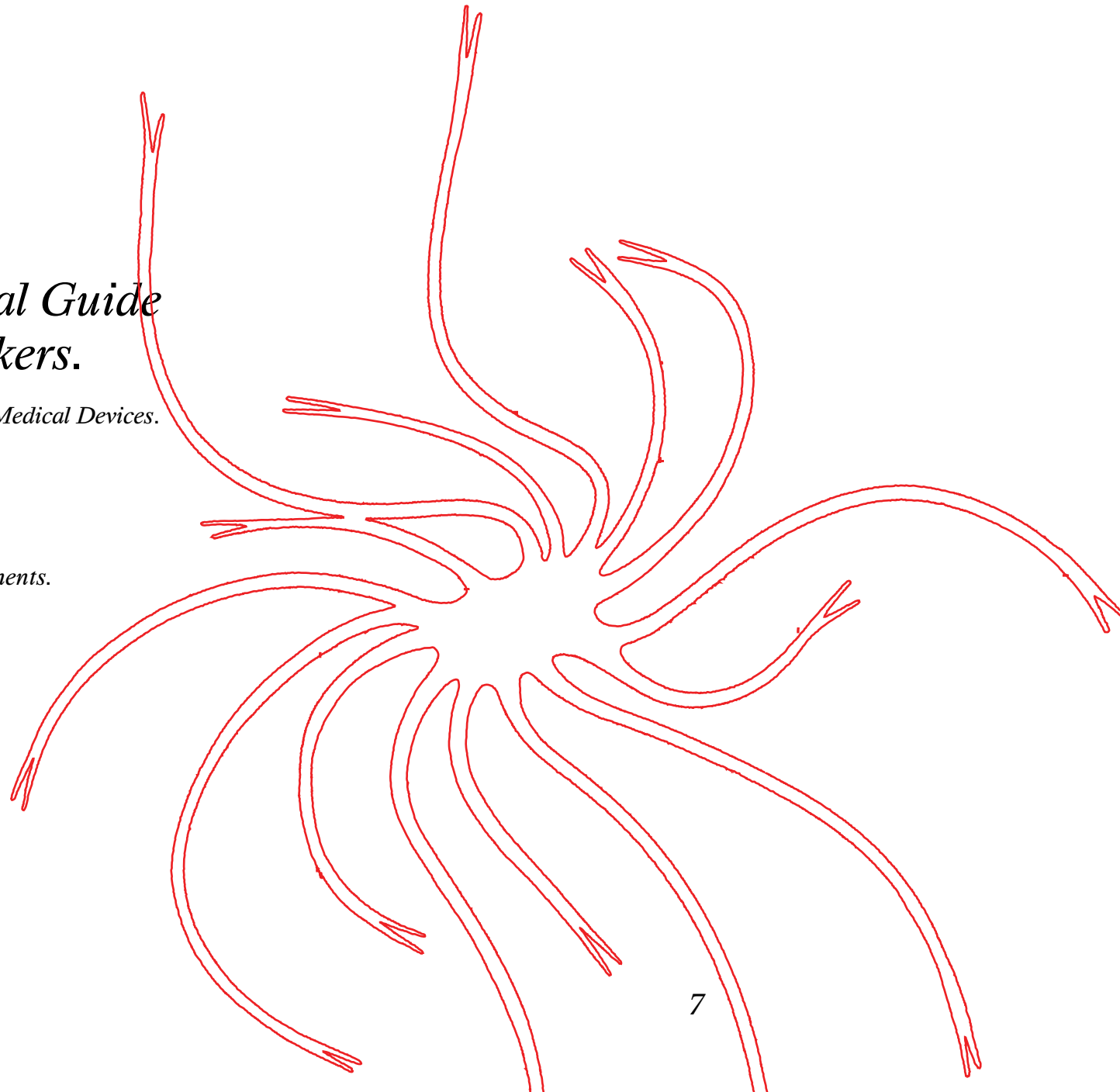
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Foreword.

Francesca Bria



Throughout Europe, we are seeing the growth of a bottom-up movement of citizens, organizations and businesses that use digital technologies to develop solutions to solve our social challenges (from the climate emergency and proactive healthcare to sustainable mobility in digital cities) through collaboration-based approaches, knowledge sharing, and open-source and privacy-friendly technologies. This approach will also help citizens regain their trust in European public institutions, integrating their collective intelligence. We call this kind of innovation Digital Social Innovation (DSI).

DSI and this idea of “technologies for social good”, which I helped define and promote at the European level, has been theorized and elaborated since 2012 through a program called “collective awareness platforms for sustainability and social innovation” and a study named DSI for Europe that I authored and coordinated when I was working at Nesta, the UK Innovation Foundation. The objective was to investigate the potential of the collective intelligence enabled by ICT to support collaborative solutions to crowdmap open data about the environment (pollution, noise, etc.), pioneer new distributed manufacturing models involving makers, demonstrate new models of social economy, participatory democracy and sustainable consumption, and develop decentralized solutions for the governance of our personal data.

Overall, collective awareness platforms and DSI programs have received some 60M€ in EU funding, with an exceptional rate of participation and success stories, demonstrating the richness of ideas and the variety of possible approaches, which are only waiting for further encouragement and support from the European Commission. The main objective of these programs is to involve policy makers, citizens and innovators consistently in one of the key aspects of our contemporary world: digital technologies. These today are not only tools to support the activities of women and men, but generate imbalances of economic and social power, as they are developed and controlled by a few and with the sole objective of profit. Starting from this awareness, we tried to highlight the urgency of identifying and helping to scale up other models of technological innovation that pursue the common good, and also the actors in Europe who are experimenting with them, in order to

redirect a form of “progress” driven only by the rules of the market.

With this objective in mind, DSI has today moved on from a definition to a network of thousands of organizations, projects and companies operating in Europe and developing bottom-up, open source and co-designed solutions. The solutions face social challenges by countering the business models that are based only on the exploitation of data or the privatization of technological infrastructures. At the center of these projects there is an interest in making technology a common good and in making its governance a distributed and democratic process in the hands of citizens and the public. They all share an interest in making a real social impact beyond the slogans of digital innovation per se.

The publication *Rebelling with Care* describes DSI in the health and care sector, reflecting on some key concepts and exploring some exemplary practices. In fact, care is a key area for DSI, if we consider the digitization of patient data management or the challenges posed by chronic and rare diseases, as well as the growth and ageing of the population. We are witnessing large private investments being made in e-health; in personalized care based on artificial intelligence algorithms and chatbots; and in proprietary medical technologies that prefigure a future in which accessibility to care services will result in a greater disparity between rich and poor.

Care – enhanced by digital tools and driven by marketing – does not produce sustainable models for governments because it is companies that manage its fundamental assets, such as the data, which are on a par with other public infrastructures such as roads, air, water and energy. The future of care cannot be left in the hands of centralized, non-transparent models.

This multitude of DSI experiments presented here provides the basis of an ambitious people-centric, rights-preserving vision across Europe, for a digital society that is green, inclusive and democratic. They should be supported in order to grow and scale up, showing that digital technologies can really contribute to communities’ empowerment, care and wellbeing.

Introduction.



The publication *Rebelling with Care* is the result of the research and dissemination activities carried out by WeMake within the framework of DSI for Europe, a project supported by the European Commission to reinforce the network of organizations using technologies to make a positive impact on society.

The DSI paradigm revolves around key concepts such as open codes and data, co-design, collaboration and social impact. Since January 2018, we have reflected upon the traction these terms could have specifically in the field of health and care practices, starting with a map of the current DSI ecosystem and an informal learning journey that has involved citizens, policy-makers, professionals and institutions.

What does it mean to develop bottom-up innovation, which is community-driven and built upon the commons, in a sector that is struggling to meet the needs of a growing and aging society, that is ruled by obsolete bureaucracies, and that is limited by proprietary technologies and top-down procedures?

We have tried to answer these questions through seven articles and seven practices that show in concrete terms the contours of the emerging and diverse new modalities of dealing with the health and care challenges of today by leveraging the empowering potential of digital technologies. In the context of this research, we came to define these different modalities, which often emerge from the strong personal needs of the people directly impacted by a specific condition, as “rebel practices”. This is because in the vast majority of cases, these practices simultaneously operate outside a market logic without asking for the full permission of official institutions, with the purpose of provoking them to change or filling the gap left by who do not innovate, with due care, in the fields of health and care provisions.

The rebellion of DSI practices in health and care then occurs within a framework that focuses on their impact beyond profit, rather than evaluating their scalability according to the levels of participation and empowerment of those affected. The practices encountered in our mapping all emphasize openness, co-design and the commoning of resources and knowledge. When technologies are involved, these are used to activate new processes and reduce superfluous

costs, thus enabling more actors to contribute to the development of effective solutions by avoiding the social exclusion and conflicts of interest characteristic of the for-profit care model. We believe the approaches they put forward might prefigure a new role for the public sector as a partner for civil society, shaping common health and care provisions for all.

Our selection of case studies aims to present a range of practices using technologies to collaboratively develop both products and processes of care. They are examples of how to find concrete answers to layered healthcare needs, beyond a mere techno-centric perspective, by using an open source process. Ranging from drones that deliver abortion pills to wearable sensors collecting data on vaginal infections, these case studies can help to clarify how this kind of DSI contains brave and novel approaches to care that can be both “pirate” and yet accountable to the collective, both collaborative and open to paradigmatic change.

Seven articles.



An abstract pattern of numerous thin, red, hand-drawn lines on a light beige background. The lines originate from a central point and radiate outwards, creating a complex, organic, and somewhat chaotic web-like structure. The lines vary in length and direction, some following straight paths while others curve or branch out.

What is (not) digital social innovation?

Valeria Graziano,
with the collaboration
of Serena Cangiano,
Maddalena Fragnito
and Zoe Romano

Over the last ten years, a growing international movement of practitioners, policy makers, activists and researchers has come together to propose a concrete and radically different vision of how technologies could help shape our common future. These people believe that technology should contribute to the common good, rather than just delivering huge profits to a handful of giant tech corporations. They want to use the opportunities offered by digitalization to address societal challenges such as environmental devastation, and to build alternative economic and political models. We call this movement “digital social innovation” (DSI).

At first glance, however, it might not be easy to detect how the movement’s conception of “social innovation” is radically different from the one hyped by many tech gurus and political consultants, which actually means more business as usual, with a touch of tech on top.

As the DSI field is growing in size and, healthily, diversity, and is beginning to enter the mainstream of public and policy consciousness, there is a real need to take stock of what its core principles actually are. When should we really be saying about DSI? And what falls outside the realms of DSI? The recent Manifesto for Digital Social Innovation¹, published last year, began to answer this question by compiling a succinct list of the core values of DSI. These are: openness and transparency; democracy and decentralization; experimentation and adoption; digital skills and multi-disciplinarity; sustainability. In what follows, we share some of our own (personal) reflections on the matter. We take a look at what DSI is definitely not, to dispel some common misconceptions around what DSI stands for.

1 – DSI Manifesto. “The Digital Social Innovation Manifesto”. www.dsimanifesto.eu/manifesto (accessed May 1, 2019).

What is (not)... digital

DSI is definitely not a call to technophilia or “techno-utopianism”—a belief that technology will provide all the answers. After all, as data scientist Cathy O’Neil and author of the best-selling book *Weapons of Math Destruction* put it, “algorithms are opinions embedded in code”², and those involved in DSI are very aware of this fact. In this sense, DSI stands precisely as an antidote to simplistic approaches that frame digital tools as either scary, inherently dangerous and responsible for all the evils in society, or, conversely, the solution to every possible problem (rather than potential tools towards solutions).

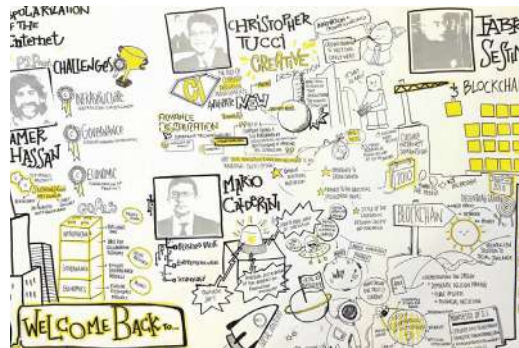
Thus, the term DSI is misused every time it is mentioned to express or encourage a vision of technology as something neutral or inevitable, and innovation as something that will spread across societies evenly and spontaneously. Instead, DSI proponents express a view that digital technologies, algorithms and automation will not in themselves solve our epochal problems like a magic pill. Instead, to paraphrase Francesca Bria, Chief Innovation Officer of Barcelona, what they do is open up scalable possibilities for coordination, knowledge, feedback, relationality and interdependency that were unprecedented before the rise of internet-enabled platforms.³

From this, it follows that DSI does not put technological experts at the core of social change either, by assigning them greater authority and capacity for insight over other perspectives.

2 – O’Neil, Cathy. 2017. “The Era of Blind Faith in Big Data Must End.” Talk at TED2017, April. https://www.ted.com/talks/cathy_o_neil_the_era_of_blind_faith_in_big_data_must_end?language=en (accessed May 1, 2019).

3 – Bria, Francesca. 2015. *Growing A Digital Social Innovation Ecosystem For Europe: DSI Final Report*. Luxembourg: Publications Office. <https://media.nesta.org.uk/documents/dsireport.pdf> (accessed May 1, 2019).

Rather, DSI calls for technologists to take on a humbler role and to challenge themselves by becoming more and more diverse in their practices, training themselves to learn from a multitude of sources and constituencies.



Finding new organizational procedures to bring together and reward different competences and modes of participation is a crucial tenet of DSI. Crucially, this ethos fundamentally differs from the widespread embrace of participatory formats that simply invite feedback from stakeholders as a form of “customer care”.

What is (not)... social

The idea of the “social” for DSI proponents and practitioners is not just a way to politely avoid mentioning “politics”. On the contrary, DSI for them is a terrain for political discussion and intervention, for creating space for the important conversations we need to have around differing, and often competing, visions for our common future.

The horizon of DSI is not a smooth space of agreement, but it characterizes the social space as one that is always traversed by a multitude of different interests and desires, which will sometimes be on opposing sides.

Actual DSI can thus only take root when the solutions it proposes address the imbalances of power and the relations of the forces shaping the social field, striving to make these relations more just, more inclusive and more democratic. This is an ethos of care that pushes actors to become more accountable to the human, the non-human and the more-than-human beings with whom they share a community of destiny.

Moreover, DSI make is possible to bring into focus the fact that deep meaningful changes in society are a product not of single enterprises, leaders or geniuses, but the fruits of sustained organized collectivities, where different actors, approaches and ways of thinking are given the opportunity to form ecologies of practice where they can influence, learn from and give feedback to each other. In this respect, DSI might overlap with, but is not the same as, social entrepreneurship. It recognizes that collaboration and cooperation—and not the much more hyped competition—are fundamental factors shaping social change. DSI does not amount to a simple belief system, insofar as social changes are not linear processes that can therefore be managed from a singular, bird-eye perspective.

It is not a matter of bringing good intentions to technological thinking, but of devising a multi-scale method for politicizing open system feedback loops in desirable ways.

What is (not)... innovation

While it has “innovation” in its name, DSI is misused every time it is spoken about as an uncritical embrace or celebration of the latest technology or whatever appears to be new and disruptive of pre-existing social arrangements.



In any constellation of start-ups constantly on the lookout for a breakthrough, we must remember that in order to know what is genuinely innovative—and why such innovation would be desirable, and for whom—we must, paradoxically, cultivate an excellent collective memory of what has been done or tried before and elsewhere.

Thus, DSI is used improperly every time it acts as an undiscerning celebration of the new. It is well known that in the for-profit world, new releases of digital machines and software often consist of little more than slight tweaks or modifications of what was already on offer. On the other hand, a common obstacle faced by initiatives that genuinely tackle critical social problems does not take place at the level of prototyping, testing and experimentation, but at the level of wider adoption, implementation, diffusion and scaling.

In a report on social innovation published last year, Geoff Mulgan, Chief Executive of Nesta, cautioned that “innovation may be much less important than the effective implementation of existing ideas or the adoption of ideas from elsewhere. (I have always advocated that governments should spend around 1% of resources on their own innovation, but that the majority of their time, money and effort should go into good implementation).”⁴

DSI instead differentiates itself from the productivist bias of existing global trends that promote the new as a way of generating opportunities for financial investment and privatization. Instead, DSI is at its most effective when it insists on the need for a long memory so that we do not mistake for “innovation” whatever appears to be new simply because we do not remember what has happened before or we do not know what is going on elsewhere. This means that DSI will sometimes look less like a series of cutting-edge shiny digital objects, and more like networks of repairers tending to social infrastructures that might be neglected, broken or suffering from systemic disinvestment.

It might be impossible today to provide a comprehensive definition of what “digital social innovation” is, as this young movement of diverse practitioners is constantly in evolution and flux. But by pointing out a few of the things we believe DSI is definitely not, we can say one thing for sure: DSI describes not just a goal, but a mode of practice.

4 – Mulgan, Geoff. 2017. “Social Innovation: The Last and Next Decade.” Nesta.org.uk, February 9. <https://www.nesta.org.uk/blog/social-innovation-last-and-next-decade> (accessed May 1, 2019).

Innovation and the paradox of for-profit care.

Zoe Romano

During an international seminar where experts from different backgrounds illustrated their perspectives on how to measure impact beyond financial indicators, one of the speakers used an Italian phenomenon to explain what he thought could represent social innovation. According to statistics¹, more than 11% of Italy's population are over 75 years of age, and this number will double by 2050. Most Italian families, especially in the northern regions, need external support to take care of their elderly. To fulfill this need, which is rarely covered by welfare support, there has been a constant growth of privately hired caregivers, directly by the family, most of them women and many of them migrants from Eastern European countries.

The spontaneous social process of hiring them—sometimes even without a contract—has become a widespread phenomenon, usually spread by word of mouth. According to statistics, 6 out of 10 caregivers are paid off-the-books and do not enjoy any form of employment benefit or accident insurance. This characteristic of being a self-organized and bottom-up arrangement of elderly care was most likely the reason why the expert at the conference lightly listed the “*badanti*” phenomenon among the examples of “social innovation”. He highlighted this bottom-up but ultimately individualistic solution without problematizing, or even referring to, the new form of labor exploitation it entails. This lack of political analysis avoids acknowledging, for instance, the psychological toll that the migrant caregivers have to endure through these working patterns, a depression so widespread that it has its own name: “Italian

1 – Istat. 2017. Il futuro demografico del paese - Previsioni regionali della popolazione residente al 2065. Istat.it, April 26. <https://www.istat.it/it/files/2017/04/previsioni-demografiche.pdf> (accessed June 25, 2019).

syndrome”.²

In a previous article we discussed some misconceptions around what the concept of Digital Social Innovation stands for, and Valeria Graziano provided a clear definition: “DSI can thus only take root when the solutions it proposes address the imbalances of power and the relations of the forces shaping the social field, striving to make these relations more just, more inclusive and more democratic.”

Only when we can witness a situation in which the balance of power changes can we say we are looking at a process of social innovation. We cannot overstate the importance of this; if we fail to recognize it, we fall into misunderstanding at best, and social-washing³ at worst.

In his book *Keywords: The new language of capitalism*, Pat Leary shows how the word “innovation” has slowly become an alternative to “progress”, embedded with a sort of prophetic meaning able to gain bipartisan consensus. This therefore makes it a very tricky word.⁴

Most companies, big and small, want to be perceived as innovative, regardless of the type of originality or newness which the service or product is actually providing. In the last few years, the word “innovation” has not only become a buzzword, but has also quickly become a standalone concept expressing a faculty to

2 – Alfaro, Gigliola. 2014. “Sindrome Italia’. È la depressione di badanti e colf.” Agensir.it, August 30. <https://agensir.it/italia/2014/08/30/sindrome-italia-e-la-depressione-di-badanti-e-colf/> (accessed May 1, 2019).

3 – Social-washing, as the green-washing, describes the initiatives of social corporate responsibility whose goal apparently is to improve the image of a company in terms of good social impact, but only for financial reasons and benefits.

4 – Leary, John Patrick. 2019. *Keywords. The New Language of Capitalism*. Chicago: Haymarket Books.

be nurtured and embraced by most organizations and institutions.⁵ A large body of research explores what exactly makes a “culture of innovation”: is it diversity and tolerance, or rather institutional arrangements and infrastructural conditions? Is it access to information or the capacity to foster environments in which meritocracy and risk-taking are really valued?



Many things called innovations are supposed to be the result of a way of thinking differently to solve a real problem; innovative solutions are generally identified as original processes or products that respond to some human need and provide changes to something established.

The key elements in this process of change are not often evident in the solution itself; sometimes it is hard even to identify who the real beneficiary is. Linked to this are a couple of considerations which are less discussed but which we should shed light on.

First of all, an actual change in any given practice should express an alteration in the power relations

5 – Fagerberg, Jan and Mowery, David C. 2013. *The Oxford Handbook of Innovation*. Oxford: Oxford University Press.

underpinning its normally adopted processes, and it is therefore never just a matter of market optimization. When, for example, the self-organized kindergarten Soprasotto⁶ in Milan started its activities, their founders knew there were many parents who needed that service.

What they had to deal with was the capacity to relate to the city administration to make them accept the new approach of action outside the traditional framework of public and private kindergartens. They had to present themselves not as a competitor to a public service, or merely a cheaper solution to private schools, but a bottom-up response to a need which neither the first nor the second could fulfill for various reasons. Parents can apply to Soprasotto association only if they are excluded from public lists, and the initiative, even after five years of operations, is still working to reach a financial balance.

Secondly, most innovations are automatically valued according to the market success and how scalable they are from a financial perspective, without digging deeply (or at all) into the potential negative externalities or implied assumptions of the innovation. For example, we have seen the emergence of many start-ups proposing high-tech anti-pollution masks for cyclists—all of which fail to recognize that pollution is a collective issue which should be solved with a long-term view and robust policy actions, pushed by citizens.

If we do not explicitly move beyond the concept of growth as a financial indicator, we fall directly into the paradox that the success of a company relies on the social issue it claims to solve never actually being solved. We need to zoom out and look at the real root causes of the issues, rather than highlighting a

6 – See Practices Soprasotto, p. 106.

shortsighted view which confuses the relationship between problem and solution in order to justify a commodified approach to social issues.

In April 2018, Goldman Sachs published a report entitled *The Genome Revolution*, analyzing the rising opportunities of gene therapy for their clients. An article from CNBC quotes the report and reveals the paradox described above:

“The potential to deliver ‘one shot cures’ is one of the most attractive aspects of gene therapy. However, such treatments offer a very different outlook with regard to recurring revenue versus chronic therapies. While this proposition [of one-shot cures] carries tremendous value for patients and society, it could represent a challenge for genome medicine developers looking for sustained cash flow.”⁷

To give a real example of the possible risks, the authors of the report continue by showing what happened when a company successfully delivered a treatment for hepatitis CC:

“GILD is a case in point, where the success of its hepatitis C franchise has gradually exhausted the available pool of treatable patients. In the case of infectious diseases such as hepatitis C, curing existing patients also decreases the number of carriers able to transmit the virus to new patients, thus the incident pool also declines ... Where an incident pool remains stable (eg, in cancer) the potential for a cure poses less risk to the sustainability of a franchise.”⁸

Goldman Sachs makes it clear: it is not the market’s

7 – Kim, Tae. 2017 “Goldman Sachs Asks in Biotech Research Report: ‘Is Curing Patients a Sustainable Business Model?’” CNBC.com, April 11. <https://www.cnbc.com/2018/04/11/goldman-asks-is-curing-patients-a-sustainable-business-model.html> (accessed May 31, 2019).

8 – *Ibid.*

objective to innovate in such a way as to provide effective cures for diseases. If this is the case, the widespread narrative around companies aiming to solve social issues is completely misleading.

This way of thinking, though, is hardly surprising. As Pat Leary shows, Joseph Schumpeter described capitalism’s capacity to mutate thanks to a special type of citizen: the entrepreneur. S/he is the one who has the power to exploit inventions to produce new commodities, often thanks to an uncritical acceptance of technologies, and belief in moral values as indistinguishable from economic ones. It is this incarnation of “innovation” which is most widespread, and gives creativity a specific class dimension: “It is almost always applied to white-collar and profit-seeking activities, although its increasing popularity in educational contexts only reflects the creeping influence of market-based models in this field.”⁹

We believe the main objective of DSI is to build an alternative narrative in which these different shades of innovation and their implications are clear.

Innovations are not created equal. Different shades of innovation express specific values and world visions, different biases and cravings. In business the most common type of innovation is usually called incremental innovation because it creates solutions a little better than the previous product or service, and protects market share with the current revenue model. One of the classic examples is when the razor was improved by adding extra blades. We can call this “business as usual”. When this approach reaches its limit, many companies invest in marketing diversification, which does not correspond to real improvements in products but can keep generating

9 – Leary, Patrick Leary. 2019. *Keywords: The New Language of Capitalism*. Chicago: Haymarket Books.

growth. The results are generally as pointless as the artificially gendered products filling the lists of websites such as BoredPanda¹⁰ and Pinterest¹¹.

When platform capitalism bloomed, most researchers started talking about disruptive innovation because new entrants challenged market leaders with new technologies and business models.



This happened with Netflix, Airbnb and Uber, and is evolving rapidly towards an Amazon effect: “if successful, a platform creates its own marketplace; if extremely successful, it ends up controlling something closer to an entire economy.”¹²

And this is the context in which power relations prevent radical innovation from happening, not because through a democratic discussion we could not achieve enough consensus on a world vision, which solutions are a small step towards, but because a discussion about a shared world vision

10 – Ko, Inga. “115 Pointlessly Gendered Products That We Can’t Believe Exist”, Boredpanda.com. <https://www.boredpanda.com/pointlessly-gendered-products-women-men>, (accessed May 31, 2019).

11 – Sociological Images. “Pointlessly Gendered Products”, Pinterest.com. <https://www.pinterest.it/sociimages/pointlessly-gendered-products/> (accessed May 31, 2019).

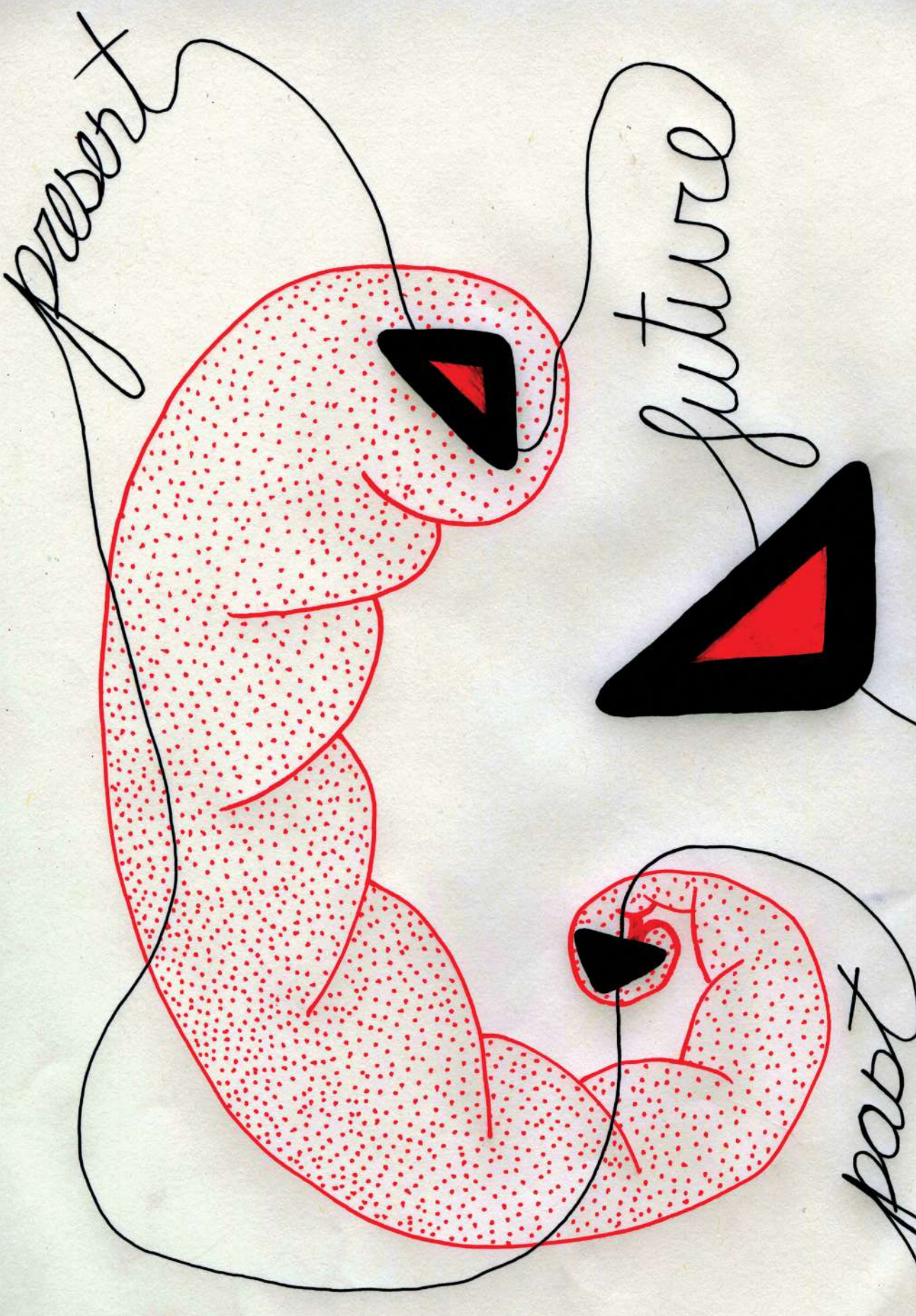
12 – Srnicek, Nick. 2017. *Platform Capitalism*. Cambridge: Polity Press.

is not taking place. Instead, on one hand we have a tightly controlled narrative, an effective story of how commodified technologies can provide solutions to narrow problems that our societies face;¹³ and on the other hand, instead of a long-term, shared direction, we have a void, revealing how capitalism is really only be a matter of expansion.

Since DSI has become more widely used in practice and in theory, and if its impact grows as we would like it to, we must become clearer about the meanings of the concepts it represents.

Language is not just a way of expressing what we see and what has to be done, but also a tool we all use to imagine and build the world we want to see.

13 – Morozov, Evgeny. 2014. *To Save Everything, Click Here: The Folly Of Technological Solutionism*. New York, NY: Public Affairs.



Alternative care and health histories.

Valeria Graziano,
with the collaboration
of Maddalena Fragnito
and Zoe Romano

The movement for DSI insists on the need for a long memory so that we do not take anything unexpected as “innovative” just because there is no awareness of what has happened before or elsewhere. This means that sometimes DSI initiatives appear not so much in the guise of sparkling new gadgets, but can present themselves as less flashy and yet effective initiatives that intervene to repair the social care infrastructures neglected by big investors.

In this article we want to briefly collect three case studies from the recent past that have seen social justice movements autonomously organizing their own medical care and assistance systems, in ways that have often led them to clash with the managerial classes in state bureaucracies, private corporations and the philanthropic third sector.

These stories of bottom-up welfare and mutual self-organization are often overlooked when talking about the future of healthcare.

On the contrary, we believe that they have a lot to offer the DSI movement precisely because they articulate a different concept of care—not as a free service, but as a process that weaves new social relationships, creating knowledge, skills and tools and rethinking the meaning of key ideas such as health and body, self-determination and trust, normality and competence. This is an aspect that we particularly want to highlight, too, because the opportunities opened up by digital technologies in the health sector are reshaping it alongside other broad historical changes, such as the dismantling of public welfare and the coming automation—supported by artificial intelligence, robotics and strong economic interests—of medical and care practices. These are dividing workers between new experts in highly automated processes and carers, who are being deskilled in

carrying out tasks defined as “high touch”.¹

In this context, it seems useful to remember the histories of mutualism that were able to organize articulated and intersectional care systems explicitly in response to equally complex systems of exploitation. In a recent article, the researcher Marie Moise has made evident the particular role played by women in forming social policy proposals that freed them from the burden of reproductive work.² Thus we discover that in France as early as 1835 the feminist Flora Tristan published a treatise on the “Need to give a good reception to foreign women”, and that in Italy the first general association of mutual aid and education of the workers was set up in 1862. Instead, the examples that we consider below date back to the second half of the last century, as this was an emblematic period that has shaped many aspects of the present social order.

Black Panthers

In the 1960s and 1970s, the central part of the Panthers’ work for the rights of black people was the organization of mutual support programs such as the “Free Breakfast for School Children Program”, which came to serve a free breakfast for over 20,000 children living in conditions of malnutrition in 60 different black communities across the USA. Other projects included drug and alcohol detoxification services; accompaniment services for the elderly who needed to visit the doctor; health education programs and even an ambulance service. In the 1970s, the Panthers

1 – Naisbitt, John, Nana Naisbitt, and Douglas Philips. 2001. *High Tech, High Touch: Technology And Our Accelerated Search For Meaning*. London: N. Brealey, 2001.

2 – Moise, Marie. 2017. “Le pratiche mutualistiche nei movimenti femministi”.

Fuorimercato.com, April 17. <http://www.fuorimercato.com/206-le-pratiche-mutualistiche-nei-movimenti-femministi.html> (accessed May 1, 2019).

volunteers managed 13 different clinics.³

During this process they gained sufficient experience in making authoritative interventions in the health policies and medical research debates of the time.

In their clinics, they carried out a mass clinical screening that significantly contributed to the study of sickle cell anemia (a genetic disease that particularly



affects people of African descent). In addition, the Panthers opposed pseudoscientific and racist-based medical testing programs, such as the UCLA Center for the Study and Reduction of Violence, which intended to perform brain operations to counteract aggressive behavior, and Tuskegee's famous experiment, in Alabama, a clinical study that infected about 600 black men with the syphilis virus without their knowledge, under the pretense of offering medical care.⁴

3 – Bassett, Mary T. 2016. "Beyond Berets: The Black Panthers as Health Activists." *American Journal of Public Health*. 106(10): 1741–1743.

4 – Fullilove, Robert. 2016. "The Black Panther Party Stands for Health", *Columbia Mailman School of Public Health*, February 23. <https://www.mailman.columbia.edu/public-health-now/news/black-panther-party-stands-health> (accessed May 1, 2019).

Act Up

Act Up⁵ is perhaps the best-known example of an international grassroots organization that has managed to impact legislation, research and standards of medical treatment for HIV/AIDS, starting from the self-organization processes of those who were directly impacted by the virus. Founded in 1987 in New York within an association of LGBT activists, the first Act Up initiatives focused on staging direct actions and protests with high media impact, such as die-ins, where they staged mass deaths. Alongside the innovative way of capturing media attention with creativity, there are at least two other aspects that make Act Up a very important example to help us think about care practices.

The first has to do with the way in which the organization managed to scale up in a very short amount of time, while staying committed to an open decision-making structure without leaders, where proposals and coordination were entrusted to an agile grouping of committees and assemblies able to make decisions democratically and autonomously.⁶

Another innovative trait of Act Up was its commitment to self-education, which focused both on scientific expertise and on understanding the rules and bureaucracies of the health system. The organization was able to modify the protocols that regulate experimental therapies through their "Parallel Track" program, which enlarged the number of participants in therapeutic trials on a voluntary basis, insisting that the patients must have full

5 – AIDS Coalition to Unleash Power. <http://www.actupny.org/> (accessed May 1, 2019).

6 – Aizenman, Nurith. 2019. "How To Demand a Medical Breakthrough: Lessons from the AIDS Fight". *Shots. Health News From NPR*. February 9. <https://www.npr.org/sections/health-shots/2019/02/09/689924838/how-to-demand-a-medical-breakthrough-lessons-from-the-aids-fight> (accessed May 1, 2019).

informed control over the design and implementation of the experiments.⁷

Italian feminist self-managed health centers



At the beginning of the 1970s, the feminist movement placed the body at the center of widely significant political reflection. In Italy, the movement loudly reclaimed the self-determination of women, opening a public polemic against what they denounced as the “medicalization” of life, the naturalization of sexuality and reproductive functions, and the “pathologization” of ways of being and desires considered “deviant”. At this time, the first self-managed health centers were opened, often in occupied spaces.

These centers were just one of the many practices that the feminist movement simultaneously developed during that period to address the lack of care and

research focused on the female body.

Self-managed health centers were accompanied by other initiatives, such as the publication of informational pamphlets, self-help and consciousness-raising practices, networks in support of abortion, and the symbolic occupations of hospitals and medical congresses to get attention of the public services. As Silvia Federici explained, one of the limitations of these feminist health policies, which ended up weakening the overall movement, was the progressive separation between the struggles for the right to abortion and a more inclusive demand for “reproductive justice”, one capable of involving those women who were denied the possibility of reproduction for economic reasons, women whose children were taken away or who were subjected to forced sterilization, for instance.

From the analysis of these and other experiences, it is possible to identify some salient features of self-organized care initiatives that have succeeded in scaling and impacting the behavior of both state apparatuses and private interests.

Communication

Self-organized care initiatives reshaped the dominant narratives framing bodies, pathologies and conditions of life, creatively challenging the messages disseminated by the media and institutional actors, rejecting both the victimization of their constituencies, but also the idea that there is something wrong with having to rely on others for continued care.

Intervention

They rejected being treated by other organizations as

7 – Crimp, Douglas. 2011. “Before Occupy: How AIDS Activists Seized Control of the FDA in 1988”. The Atlantic, December 6. <https://www.theatlantic.com/health/archive/2011/12/before-occupy-how-aids-activists-seized-control-of-the-fda-in-1988/249302/> (accessed May 1, 2019).

a cheap replacement for care professionals, refusing to be given responsibility without power. Volunteers and activists never ceased to press institutions to invest more and more effectively in excellent services accessible to all, contesting the idea (sometimes presented as inevitable) that health should be managed from the perspective of saving money and cutting back.

Community

They spoke not only to patients and their families, but were also able to involve different actors, insisting on conceiving health as a matter that impacts everyone's living conditions, from within a perspective of extended civil solidarity.

Impact

They freed themselves from the idea that it is always necessary to please everyone or to minimize conflicts to impact social changes. To achieve their goals, bottom-up care initiatives developed at times strong strategies, exerting continual pressure on institutions by calling out unjust behavior. These forms of activism revealed that scientific and medical communities are not necessarily the neutral entities they claim to be, but can be marked by prejudice and discriminatory ideologies. Women, homosexuals, the disabled, the poor, the mad, foreigners and black people have often not been considered suitable subjects for participating in decisions taken about their bodies.

Diffused knowledge

They invested in continuous self-education and research activities, which enabled them to understand

and intervene competently in official scientific debates and influence research. Another era of continuous training concerned their in-depth knowledge of the mechanisms and logistics that govern healthcare systems, including the role of large private interest groups in the management of public health.

Integrated approach

They problematized the idea that it is sufficient to deal with only one aspect of people's conditions, or that is enough to identify a standard single procedure that works for everyone to solve health problems—an approach that has often been followed by the pharmaceutical sector, which is interested in creating products with the widest possible market, and by state bureaucracies, due to an entropic lack on investment in change.

Taken together, such distinctive traits highlight how deepening the knowledge of self-managed care experiences from the past is a valuable exercise for sketching the contours of the new inclusive, democratic and sustainable organizational practices made possible by open technologies, especially given the role of medical knowledge, historically, as a tool to discipline the weakest. Fablab, makerspaces and online communities are becoming reference points for responding to care and health issues. They do not merely produce solutions, but generate a complex ecosystem of collaborations beyond the dualisms of public/private or profit/non-profit.

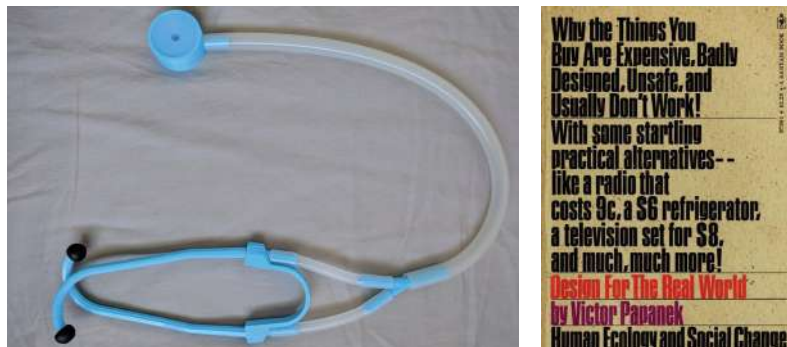
In the next articles, we will draw connections between the legacy of these examples and the current experiences that we are embedded in and that we are animating, trying to analyze how lowering the barriers for using digital technologies is changing the forms of organization and the dissemination of new practices of welfare.



Co-design as competitive advantage.

Serena Cangiano

When designing a technological object, one method is to actively involve people, the so-called end-users, in the process. Since the 1970s, this method has helped anticipate the negative impact of technology on our individual and collective lives. In a sector dominated by techno-solutionist approaches to innovation—namely, innovation that focuses mainly on the development of a product without any reflection



on the political and social impact at systemic level—real co-design is rarely applied, and is too often reduced to a buzzword. However, in the context of social impact-driven innovation, this method is well integrated into projects that develop technologies with a positive impact on collectivities, although it sometimes refers to niche processes, treated at times as slightly “hippie” alternatives carried out by “do-gooders”.

In this article, we discuss, as a provocation, a different perspective: co-design could offer a “competitive advantage” to social innovation projects using technology, and work as an approach that provides resilience, which is usually lacking in profit-driven innovation.

Anyone who has ever attended a course or a workshop on how to design an innovative business

model has experienced the use of some “design thinking” tools such as the so-called “canvases”¹—white sheets of paper structured in blocks to be completed in order to define key aspects of a business idea. From the key value proposition to the way the product is distributed, the canvas guides the entrepreneur to understand, step by step, the best strategies to move from idea to customer.

In the context of DSI, a project often comes to life through a system of bottom-up practices.

The canvas method is replaced by dialogue and direct participation by those who want to solve a problem which companies and/or technologies are not interested in, typically because (according to investors, at least) there is no market for a solution.

In fact, the processes and practices of DSI should be considered, in our opinion, a competitive advantage, because they transform the social impact of a project into the only effective strategy to tackle complex problems in the context of resource scarcity. From this viewpoint, DSI escapes the widespread “good-hearted” narrative that make it look like a “hippie” alternative to digital innovation and it can position itself among the planning process with the greatest chance of success.

The semantic drifts of co-design

To support our perspective, it is useful to highlight first of all how words such as co-design and co-creation exist today in a situation of strong semantic conflict. Indeed, in the context of technological

1 – Strategyzer. “The business model canvas.” *Strategyzer.com*. <https://www.strategyzer.com/canvas/business-model-canvas> (accessed May 1, 2019).

innovation, those words are often buzzwords mistakenly used to communicate the “user-centric” quality of a project, or to suggest that a solution has been modelled and tested with the final users, thus increasing the chances of its success in the real marketplace. In these contexts, co-design actually just stands for “user-centered design”.²

In the context of social innovation, however, the term co-design indicates that a project stems from an inclusive process, from an open and horizontal conversation between constituencies and designers, and from a collaboration nourished between diverse communities.

This is certainly the most correct meaning, though it sometimes entails a certain depreciation of the co-design method because it seems solely to describe a specific type of innovation, that pursued by “do-gooders”. Rather, we believe that co-design methods represent a real competitive advantage for DSI projects.

Back to the future: co-design in the 1970

To further explain the concept of co-design, let us have a look at the past, especially at the history of design in the 1970s. In 1971, Victor Papanek, an Austrian professor based in the United States, and a pioneer of sustainable and social design, wrote *Design for the Real World*, bringing for the first time a political perspective to industrial design. In the book, Papanek criticized design practices for being

too consumption-driven, and for generating too much waste. He spoke instead of do-it-yourself design and the repair ethic, demonstrating that it was possible, for example, to design an FM radio with simple, easily repairable components for just 9 cents:

“Design must be an innovative, highly creative, cross-disciplinary tool responsive to the needs of men. It must be more research-oriented, and we must stop defiling the earth with poorly designed objects and structures.”³

With Papanek, we see the beginning of a political discourse on design with a social impact, in which the attention given to the latter is not just an exotic, alternative methodology, but an approach to the design of all kinds of everyday objects. His work first demonstrated how co-design can offer a sort of a guideline to avoid creating useless products that have only an aesthetic value, and focus instead on the real needs of constituencies, opposing the idea that individuals are only consumers. Papanek’s book should be re-read today, especially in the midst of our techno-solutionist era in which start-up companies designing useless products are abundant.

Outside academic circles and faculties of design, few people are aware that co-design (with the users) and participatory design (with all the stakeholders of a project) also have their roots in the 1970s, in Scandinavia, within studies that explored the integration of technologies within workspaces. In project UTOPIA⁴, for instance, a group of researchers led by Pelle Ehn developed a set of tools to engage both workers and their unions in a process of

2 – IDEO. 2009. “Design Kit: The Human Centered Design Toolkit.” *Ideo.com*. <https://www.ideo.com/post/design-kit> (accessed May 1, 2019).

3 – Papanek, Victor. 2005. *Design for the Real World*. Chicago: Chicago Review Press, 4.

4 – Ehn, Pelle. 1988. *Work-Oriented Design of Computer Artifacts*. Stockholm: Almqvist & Wiksell, 327–350.

redefining the work environment, by giving them a voice on how to improve the quality of their work and life.

“This is an inquiry into the human activity of computer designing artifacts that are useful to people in their daily activity at work. The emphasis is on opportunities and constraints for industrial democracy and the quality of work.”⁵

In the 1970s, when computers were on the verge of invading every factory and office, a group of researchers understood that, to avoid a negative impact on people’s lives, it was necessary to open up the design process, starting from the phase of ideation, to involve the users who were the real experts in the problem impacting their living conditions. In co-design projects, the process of connecting human life with the impact of technologies becomes a common, that is, a space owned by everyone and where everyone can actively operate and contribute to its definition.

The failure of non-social impact-driven innovation

In digital innovation events such as hackathons and meetups, words such as “co-creation” and “co-design” are often invoked. Very rarely, however, do people put these methodologies into practice to generate novel technological devices. A proof of this lack of correlation between the ideas generated in the context of technological innovation and the solution of complex societal problems can easily be found in the statistical data about the failures of startups. In Silicon Valley alone, 50% of companies (a

5 – *Ibid.*

percentage that increases in other countries) fail because of a lack of correspondence between the idea or the product with the problems of the real world or the actual needs of a community.⁶

When it comes to the definition of singular and collective needs, a project that starts from an open dialogue with all the actors implicated in a given issue is much more likely to succeed than a project designed *a priori* by a small group of people who have no experience of that problem. Although this might sound banal, this latter approach to design might be actually the leading cause of start-up failure.

This scenario, we believe, shows that the start-up system is mostly a platform supporting the circulation of money, rather than a sustainable strategy for the development of technology. As a consequence, it is possible to state that the application of co-design and participatory methods for approaching social problems can offer a strong competitive advantage to DSI projects.

The first world disadvantage

In the field of humanitarian aid (e.g. for refugee crises or in response to natural disasters), it is common for technologies to be designed and developed with care. These projects face complex problems in specific contexts where there is an evident scarcity of resources. In the health and care sector, projects are based on the use of open-source mobile technologies and co-design processes that involve doctors, patients (not always directly) and big organizations with different missions: examples of projects are Tarek

6 – CBIInsight. 2018. The Top 20 Reasons start fail. *CBIInsights.com*, February 2. www.cbinsights.com/research/startup-failure-reasons-top (accessed June 26).

Loubani's 3D printed stethoscope⁷ or the open-source mobile diagnosis EchOpen.⁸ These cases make us reflect on important questions: could all the devices, platforms and apps of a so-called "first world" country be designed in this way—that is, designed to be low-cost, accessible to all and respectful of data privacy? In the "first world", innovation often works differently, bringing with it waste, loss of money, pollution and disrespectful data trading. Can we say that, for the first time in history, we are in a situation of disadvantage compared to so-called developing countries?

The competitive advantage of the community

When it comes to community engagement, social innovation projects can be defined as such precisely because they are generated *with* or *by* an existing community and never for a community. In social impact projects, the community is not conceived in retrospect and does not correspond to a column in the spreadsheet of the financial plan, such as, for example, the total investment in Facebook and Google advertising for reaching the target audience which, according to marketing, is called "community". In innovation projects, the community costs money and can disappear as soon as the investors' capitals runs out. Instead, in DSI projects, the community is always organic and cannot be bought, and for this reason, represents a real competitive advantage. Think, for instance, of the famous Arduino project, the open-source board for DIY electronics: the online Arduino forum hosts about 750,000 people and the community grows without

7 – Mackay, Crystal. 2018. "Clinically-Validated 3-D Printed Stethoscope." *ScienceDaily.com*, March 14.

8 – See Practices EchOpen, p. 102.

large investments by the company, which is still very competitive even after the rise of many other open hardware companies in the same sector.

New criteria to support innovation

In one of the most important books on open design, John Thackara defined openness as "a matter of survival".⁹ In the conclusion to this article, we would like to recall Thackara's point: the choice to apply co-design is a question of survival because it generates a competitive advantage over those innovation projects where the resolution of complex problems is approached only through a techno-solutionist perspective and where the narrative around the community engagement is used as a marketing strategy to impact the turnover alone.

We close our reflection on the competitive advantage of social impact-driven innovation by imagining a future in which the policies and the ecosystems of actors that support innovation (public funding programs, investors, incubators and universities) will consider the application of "non-simulated" co-design processes as a criterion of evaluation. In this future, a proposed solution based on a hypothesis that has never been validated through real processes of engagement with all those affected—one that therefore excludes the final beneficiaries or users from the ideation phase—will be left behind in the ranking. This will happen because DSI projects will be more likely to last over time and trigger positive dynamics on a political and social level, as well as on the economic one.

9 – Thackara, John. 2012. "Into the Open." In *Open Design Now: Why Design Cannot Remain Exclusive*, edited by Bas van Abel, Lucas Evers, Roel Klaassen and Peter Troxler. Amsterdam: Bis Publisher, 42–45.



Body, Politics and Molecules.

Maddalena Fragnito

The biopolitical history of hormones is longer than one might expect. As early as the end of the 19th century, serums made of animal hormones were used to treat males who were considered too “feminist”¹ and females seen as too “masculine”. In the laboratories of that time, hormones were already seen through gendered lenses: estrogens were considered feminizing, while testosterone was seen as masculinizing.



From these early experiments, an industry using animal extracts began to develop in order to treat whatever was defined as a behavioral issue, such as masculinity, femininity, homosexuality or depression.

The development and reinforcing of these kinds of somatic fiction go hand in hand with the commodification of specific molecules: the very definition of depression would not even exist without

1 – In 1871 the word “feminism” was first used by a young French doctor named Ferdinand-Valère Fanneau de La Cour, in his doctoral thesis *On Feminism and Childishness in Tuberculosis Patients*. Feminism here is understood as a pathology of men suffering from tuberculosis that produces a feminization of their body. Later the term “feminism” was used as a term to accuse the men who supported women’s battles for the right to vote. Cfr. Preciado, Paul. 2019. “La Rivolta nell’Epoca Tecnopatriarcale.” *Kabulmagazine.com*, May 11. Translation by the author. http://www.kabulmagazine.com/paul-b-preciado-rivolta-epoca-tecnopatriarcale/#_ftn1 (accessed May 31, 2019).

the synthesis of serotonin, while the “feminist” pathology would not be there without the synthesis of testosterone. These “pathologies” then spread and began to be treated by pharmaceutical and petrochemical companies—such as Ciba, Organon and Shering—who were able to foresee their potential profitability.

Early experiments related to these new illnesses were conducted on animals, but also on women, poor and indigenous populations. For instance, from 1940 to 1970, a petrochemically derived drug named Diethylstilbestrol was given to pregnant women in order to prevent spontaneous abortions. This was done before knowing the drug was carcinogenic and produced genetic modifications that could have an impact across the following three generations.

The contraceptive pill, regularly administered from the 1960s, was later discovered to have several not negligible pathological implications (obesity, depression and cancer, among others), even though these were seen as less “dangerous” than childbirth mortality (especially in countries with poor access to reproductive healthcare).

However, hormones do not just concern the reproductive sphere; they surround and contaminate us whether we are aware of it or not. Indeed, the petrochemical industry is the biggest producer of synthesized molecules through the diffusion of agricultural pesticides. For instance, Atrazine (a substance capable of modifying the sex of frogs and fishes²) is found in 94% of American drinkable

2 – Sanders, Robert. 2010. “Pesticide Atrazine Can Turn Male Frogs Into Females.” *Berkeley.edu*, March 1. <https://news.berkeley.edu/2010/03/01/frogs/> (accessed May 31, 2019).

water.³ PCB (a molecule patented by Monsanto)⁴ is considered to be the most pervasive chemical compound in the world as it is detectable in all living bodies on the planet. BPA,⁵ a fundamental molecule for the synthesis of some kinds of plastic, was first tested on women, even before Diethylstilbestrol, because of its estrogenic effects. Despite several studies confirming its toxicity, this molecule is still in circulation through BPS,⁶ a new synthesis that it is not (yet) obligatory to trace.

In this context of “molecular colonization”⁷ one wonders not only what is “normal” and what is “natural”, but also what our level of awareness of our bodies and their relation is with the surrounding environment. Indeed, we are all contaminated by endocrine molecules that affect our reproduction, its related organs and, ultimately, our overall hormonal balance: we are battlegrounds for programs of “evolutionary” and control engineering.

3 – Pesticide Action Network North America. “Pesticide Residues Found by the USDA Pesticide Data Program”, *Whatsomyfood.org*, <http://www.whatsonmyfood.org/food.jsp?food=WR> (accessed May 31, 2019).

4 – Servizio Interdipartimentale per le Emergenze Ambientali. Settore Studi e Valutazione (APAT). 2006. “Diossine Furani e PCB”, *Salute.gov.it*. http://www.salute.gov.it/imgs/C_17_pubblicazioni_821_allegato.pdf (accessed May 31, 2019).

5 – Konieczna, Aleksandra, Rutkowska, Aleksandra, Rachon, Dominik. 2015. “Health Risk of Exposure to Bisphenol A (BPA).” *Roczniki Panstwowego Zakladu Higieny*, 66(1):5–11. <https://www.ncbi.nlm.nih.gov/pubmed/25813067> (accessed May 31, 2019).

6 – Qiu, Wenhui, Hongyan Zhan, Jiaqi Hu, Ting Zhang, Hai Xu, Minghung Wong, Bentuo Xu, and Chunmiao Zheng. 2019. “The Occurrence, Potential Toxicity, and Toxicity Mechanism of Bisphenol S, a Substitute of Bisphenol A: A Critical Review of Recent Progress.” *Ecotoxicology and Environmental Safety*, May 30, 173: 192–202.

7 – Tsang, Mary. 2017. *Open Source Estrogen: From Biomolecules To Biopolitics... Hormones With Institutional Biopower!* (Doctoral dissertation, Massachusetts Institute of Technology).

*Testosterone, disappeared (for the sins of others)*⁸

How do we reconcile the fact that we live in territories contaminated by synthesized molecules but, if we want to use hormones to start or continue a transition,⁹ we encounter difficulties that put our lives at risk?

Since the beginning of 2019, testosterone has disappeared from Italian pharmacies. In their latest bulletin,¹⁰ the Italian Drug Agency (AIFA) announced an official “shortage” of medicines such as Nebid (Bayer), Testoviron (Bayer) and Sustanol (Aspen). As stated on AIFA’s webpage,¹¹ the temporary lack of vital drugs for specific pathologies on the national market is monitored through a specific procedure. What is meant by a “shortage” is that a given medicine cannot be found throughout the country because the authorities cannot guarantee appropriate and uninterrupted distribution.

However, a real “shortage” of a drug has to be distinguished from its “temporary unavailability”, which is due to market dynamics linked with its distribution. European regulations do not distinguish

8 – This paragraph of the paper was made possible by the contribution of Yuri S. D’Ostuni and Samuel Spano, who, starting from their own experience, helped me to understand why in Italy access to testosterone is never entirely guaranteed.

9 – Transition is defined as the path that leads an individual to stop living the role relative to their biological sex in order to arrive at living in the gender identity of choice. Wikipedia. 2019. “Transitioning_(transgender)”. [https://en.wikipedia.org/wiki/Transitioning_\(transgender\)](https://en.wikipedia.org/wiki/Transitioning_(transgender)) (accessed May 22, 2019).

10 – AIFA, Agenzia Italiana del Farmaco. 2019. “Elenco dei medicinali carenti.” *Aifa.gov.it*, http://www.aifa.gov.it/sites/default/files/elenco_medicinali_carenti_03.05.2019.pdf (accessed May 31, 2019).

11 – AIFA, Agenzia Italiana del Farmaco. 2019. “Carenze e indisponibilità.” *Aifa.gov.it*, <http://www.aifa.gov.it/content/carenze-e-indisponibilit%C3%A0> (accessed May 31, 2019).

between “shortage” and “unavailability”, even though the two are very different. Shortages are linked to productive problems and are often related to the non- profitability of a “out-dated” drug, whereas a temporary unavailability is related to the phenomenon of “parallel trade”, a practice that takes advantage of the price differences between different markets.



If a pharmaceutical company makes more money from selling a given medicine in one country rather than another, it is inclined to sell the total amount required by both countries to the more profitable market. This forces the latter to buy the product—under emergency conditions and at an increased cost—through the public health systems that are granted “import authorization for similar uses abroad”.¹²

Parallel trade is the mechanism through which taxpayers from less affluent countries end up filling the coffers of the big pharmaceutical monopolies.

¹² – Quotidiano Sanità. 2019. “Carenza farmaci Testoviron e Sustanon. Aifa ha autorizzato l’importazione dell’analogo medicinale commercializzato all’estero.” *Quotidianosanita.it*, April 19. http://www.quotidianosanita.it/governo-e-parlamento/articolo.php?approfondimento_id=12921 (accessed May 31, 2019).

Despite the fact that some countries have repeatedly brought lawsuit against companies such as Bayer, which has been specifically accused of this type of fraud¹³, the company has always been acquitted for lack of evidence.

Beside fraud, the unavailability of medicines encourages the production and sale of testosterone of dubious origins¹⁴, further limiting the possibility for transgender people to access safe pathways for hormone intake. Indeed, this type of drugs is only prescribed as therapy for hypogonadal¹⁵ cisgender (when people feel their birth-assigned sex and gender match their gender identity) people; therefore, so-called “gender dysphoria” (when people feel their birth-assigned sex and gender do not match their gender identity) is not among the authorized conditions for the use of these medicinal products in Italy, as in most of the rest of the world.¹⁶

¹³ – Desogus, Claudia. 2011. “Antitrust Issues in the European Pharmaceutical Market: An Economic Analysis of Recent Cases on Parallel Trade.” *Working Paper n° 60*. Center for Research in Health and Economics. https://www.upf.edu/documents/3223410/3287206/wp60_desogus.pdf/dcff03ed-451b-4c79-a937-e54b98f8d038 (accessed May 31, 2019).

¹⁴ – Quotidiano Sanità. 2017. “Farmaci nel dark web. È allarme OEDT ed Europol. In Europa mercato da 80 milioni di euro.” *Quotidianosanita.it*, November 30. http://www.quotidianosanita.it/scienza-e-farmaci/articolo.php?articolo_id=56509 (accessed May 31, 2019).

¹⁵ – Hypogonadism is a pathology of the endocrine system that involves an inadequate secretion of sex hormones (e.g. testosterone and estrogen) by the gonads (ovary or testis).

¹⁶ – Smiley, Adam, Aisa Burgwal, Carolina Orre, Edward Summanen, Isidro García Nieto, Jelena Vidic, Joz Motmans et al. 2017. “Overdiagnosed but Underserved. Trans Healthcare in Georgia, Poland, Serbia, Spain, and Sweden: Trans Health Survey.” *Transgender Europe*. https://tgeu.org/wp-content/uploads/2017/10/Overdiagnosed_Underserved-TransHealthSurvey.pdf (accessed May 31, 2019).

Therefore, if on the one hand the recent depathologization of gender dysphoria¹⁷ can be seen as a cultural and civil conquest, on the other it has left a definitional void that needs to be filled to guarantee access to medical care to everyone. In fact, this void pushes people who take hormones for gender transition to do so “off label”, meaning that they become non-existent. Moreover, hormones are not refundable from the Italian National Health System and it is difficult to catalogue them as class A, meaning lifesaving, drugs. It is assumed that the life of a hypogonadal male is not a risk because of a temporary unavailability of testosterone, but its present classification (class C) does not protect trans people from the serious consequences that occasional testosterone intake can generate: a high risk of thrombosis and chronic osteoporosis, not to mention depression and suicide.

One of the factors that complicates this classification even further relates to the lack of data. Under the current legislation, AIFA can consider the introduction of a new therapeutic classification for a drug only if the pharmaceutical company that holds the marketing authorization (in Italy, AIC) submits a request for an extension of therapeutic indication, supported by related scientific evidence.¹⁸ The problem

17 – Open Access Government. 2019. “WHO removes ‘Gender Identity Disorder’ diagnosis.” *Openaccessgovernment.org*, May 28, <https://www.openaccessgovernment.org/gender-identity-disorder/65852/> (accessed June 3, 2019).

18 – On the other hand, law n. 648 of December 23, 1996 allows medicines bought by the Italian health service to be used for a different therapeutic indication than the one authorized, following a request from the Technical-Scientific Commission of AIFA, from patient associations, scientific societies, health authorities, universities and scientific institutions for admission and care, after the careful evaluation of the scientific evidence in support. D.L. 23 December 1996, n. 648, “Conversione in legge del decreto-legge 21 ottobre 1996, n. 536, recante misure per il contenimento della spesa farmaceutica e la rideterminazione del tetto di spesa per l’anno 1996.” <http://www.camera.it/parlam/leggi/96648l.htm> (accessed June 3, 2019).

is that there is no systematically collected data, because gender transition does not follow a specific medical procedure. There is no platform for sharing data on this “pathology” and this, in turn, affects medical research and access to care, as well as increasing the risks trans people face in emergency situations: for instance, during a serious accident, lacking access to patient’s records and data, a physician could worsen their condition due to wrong therapeutic procedure.

Data collection is undoubtedly fundamental, but is made difficult by the lack of clarity about the therapeutic process. Perhaps if it is now universally clear that it is not gender that has to be referred as dysphoric but the hormonal balance needed by a person to pursue a fulfilling life, what if instead we introduce an “hormonal dysphoria (or discrepancy)” for every individual who needs lifesaving drugs?

In summary, the temporary unavailability of testosterone in Italy, whose synthesis is a patent owned by Bayer, is the result of an illegitimate monopoly that guarantees large periodic investments paid for by taxpayers and trans people, because they find themselves buying the drug, which may fluctuate in price. But if those who pay taxes do not have any idea of these trends, those in need of hormonal treatment know exactly who the “sinners” are.

Furthermore, the problem that emerges following the story of testosterone reflects a more general problem, a pharmaceutical issue common to various pathologies. The phenomenon of a parallel trade, in fact, affects many other types of life-saving medicines, such as drugs for cancer therapies, cystic fibrosis and diabetes, as made clear by recent examples like

“Caravan for Canada”,¹⁹ groups of Americans with diabetes who form caravans of cars to go to buy insulin in Canadian pharmacies for 90% less than the US version (they are clinically identical), because in Canada pharmaceutical prices are set by a government agency called the Patented Medicine Prices Review Board. Further in the past, but perhaps better known, is the death of thousands of people from Aids in South Africa at the turn of the millennium, simply because people could not afford medicinal treatment costing 10.000 dollars per year.

These emergencies are generated by the fact that every new drug is patented and no one else can manufacture or sell that drug for a period of at least 20 years. Without competition, pharmaceutical companies can decide the price they want and, to date, they have defended themselves by claiming that the high costs are due to the research and development involved. However, as there is no transparency about how these companies invest their capital, no one can verify whether these claims are true.

Civil society groups, projects and organizations such as Fix the Patent Laws²⁰, Fair Pricing of Medicines²¹, TAC²² and Knowledge Ecology International²³ have been working for years on accessibility to medical treatments, while a final proposal delivered to the World Health Organization (WHO) comes from the health minister of the current Italian government, Dr.

19 – BoingBoing. 2019. “Americans with diabetes are forming caravans to buy Canadian insulin at 90% off.” *BoingBoing.net*. May 9. <https://boingboing.net/2019/05/09/life-or-death.html> (accessed May 31, 2019).

20 – Fix The Patent Laws. <https://www.fixthepatentlaws.org> (accessed May 31, 2019).

21 – World Health Organization. “Fair Pricing of Medicines.” https://www.who.int/medicines/access/fair_pricing/en/ (accessed June 1, 2019).

22 – Treatment Action Campaign. <https://tac.org.za/> (accessed June 1, 2019).

23 – Knowledge Ecology International. <https://www.keionline.org/> (accessed June 1, 2019).

Giulia Grillo, which requires a resolution to improve transparency in the drug market. If this resolution is approved this year at the World Health Assembly,²⁴ governments could start asking companies to reveal the annual costs of research and development, their production costs and, finally, the profit margins of individual pharmaceutical products.

However, sticking to the current system will never bring universal access to drugs; some people will always survive and others will not. Instead of trying to regulate and modify the margins of a monopoly-based system, we need a different system, one more similar to the mission set out by Open Source Pharma: “Create a movement that includes existing initiatives and develop an alternative, comprehensive, open source pharmaceutical system driven by principles of openness, patient needs, and affordability.”²⁵

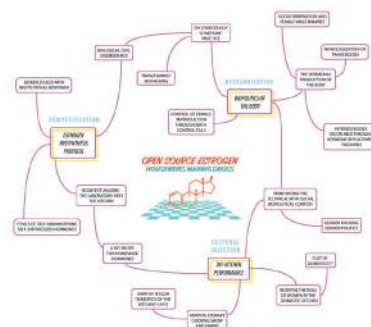
Among these topics, there is an argument within trans people networks about the need to become a spokesperson for more fragile categories—such as terminally or chronic patients—and to intervene in the European institutions to promote transnational laws for reducing the margin of companies playing with people’s lives, as well as the desire to create new types of “safe and multipurpose” counseling spaces, and to build open-source platforms for data sharing.

24 – World Health Organization. “World Health Assembly.” <https://www.who.int/about/governance/world-health-assembly> (accessed May 30, 2019).

25 – Open Source Pharma. <http://www.opensourcepharma.net> (accessed May 30, 2019).

Open source estrogen

Estrogen hormones are not so in the spotlight as testosterone; in fact, not being used for sport (and war), there is no such a lucrative black market for them.



An article entitled “Big Boring Bureaucratic Revolution”, published following the Istanbul Innovation Days, indicates that among the “six areas of experimentation” that the intersection between technological innovation and civic participation produce is one representing the encounter between art and science fiction: “There is a range of interesting initiatives looking at the arts, and in particular at science fiction, as a source of potential directions and lenses to understand the nexus of human and machine rights, emotional and genetic surveillance and human rights, impact of 4.0 technologies on human rights and law.”²⁶

26 – Johar, Hindi. 2018. “NextGenGov (the Big Boring Bureaucratic Revolution).”

Darkmatterlabs.org, Jul 27. <https://provocations.darkmatterlabs.org/nextgengov-the-big-boring-bureaucratic-revolution-39ccc3a6c9f8> (accessed May 30, 2019).

In this sense, Open Source Estrogen,²⁷ a collaborative project led by the artist Mary Maggic, stands between citizen science and speculative design and has the ambition to develop DIY/DIWO (Do it with Others) protocols for the “domestic” synthesis of hormones, as a response to the strong control by governments and institutions over human bodies.

If people do not receive adequate or sufficient drugs, can these be synthesized in a domestic environment?

How can we re-contextualize laboratory biochemistry into an open-source “recipe” that hacks estrogen to guarantee equity and accessibility?

The project aims to hack hormones present in our body and the environment, creating non-institutional access to therapy, as well as raising awareness of how human bodies are regulated by the culture and the market. From estrogen detection and extraction to its synthesis, these recipes are forms of social resistance, awareness tools and DIY therapies that put gender hacking into practice. If institutions and medicine produce fictions about the way bodies should be divided by gender and how they should reproduce, heal and die, a domestic methodology of care, such as that promoted in Mary Maggic’s workshops, sees becoming molecularly mutant as a form of liberation of the body: “In our scientific methods, we do not seek techno-solutionism. With the creation of a DIY estrogen protocol, increased endocrinological know-how and body sovereignty, the project becomes a public platform for discussing the ethics of self-administered self-synthesized hormones. What physiological dangers have arisen through potential overdosing and exposure to impurities, and what will

27 – Maggic.ooo. 2015. “Open Source Estrogen”. <http://maggic.ooo/Open-Source-Estrogen-2015> (accessed May 30, 2019).

people trade in return for wrestling greater control over their bodies?”²⁸

Evidently, when practices of this type are disconnected from democratic political instances, they can produce horror laboratories, such as the rise of popularity among teens of DIY gene-editing kits bought and administered individually through the



web, but they become fundamental when contextualizing and promoting a framework against cultural stereotypes and the monopoly of patents and access to health. Discussing this with Yuri S. D'Ostuni and Samuel Spano, the idea of synthesizing their own testosterone dose would become interesting to the extent that it is a way of bypassing Bayer's patent and generating an open source synthesis of a drug in a more accessible way, creating life and shared knowledge.

A recent article by former UK civil servant Kit Collingwood-Richardson,²⁹ featured in an edition

of Nesta's Lab Notes,³⁰ cites nine ways in which public services could respond more efficiently to ongoing social transformations. Point 7 is “Co-create policy with those impacted in the room” and—starting from the assumption that “Nothing About Us Without Us!”—discusses the need to include patients in the design of solutions that are sought, meaning listening to those who will be affected by these solutions for their entire lives: stop making (wrong) decisions in “white rooms” far from reality white rooms, and between people who do not have specific experience on the topic.

And yet, as long as government policies are unable to transform themselves from within, we will apply all our biopolitical powers to creating democratic and imaginative forms of social reproduction, resisting the commodification and privatization of the right to live.

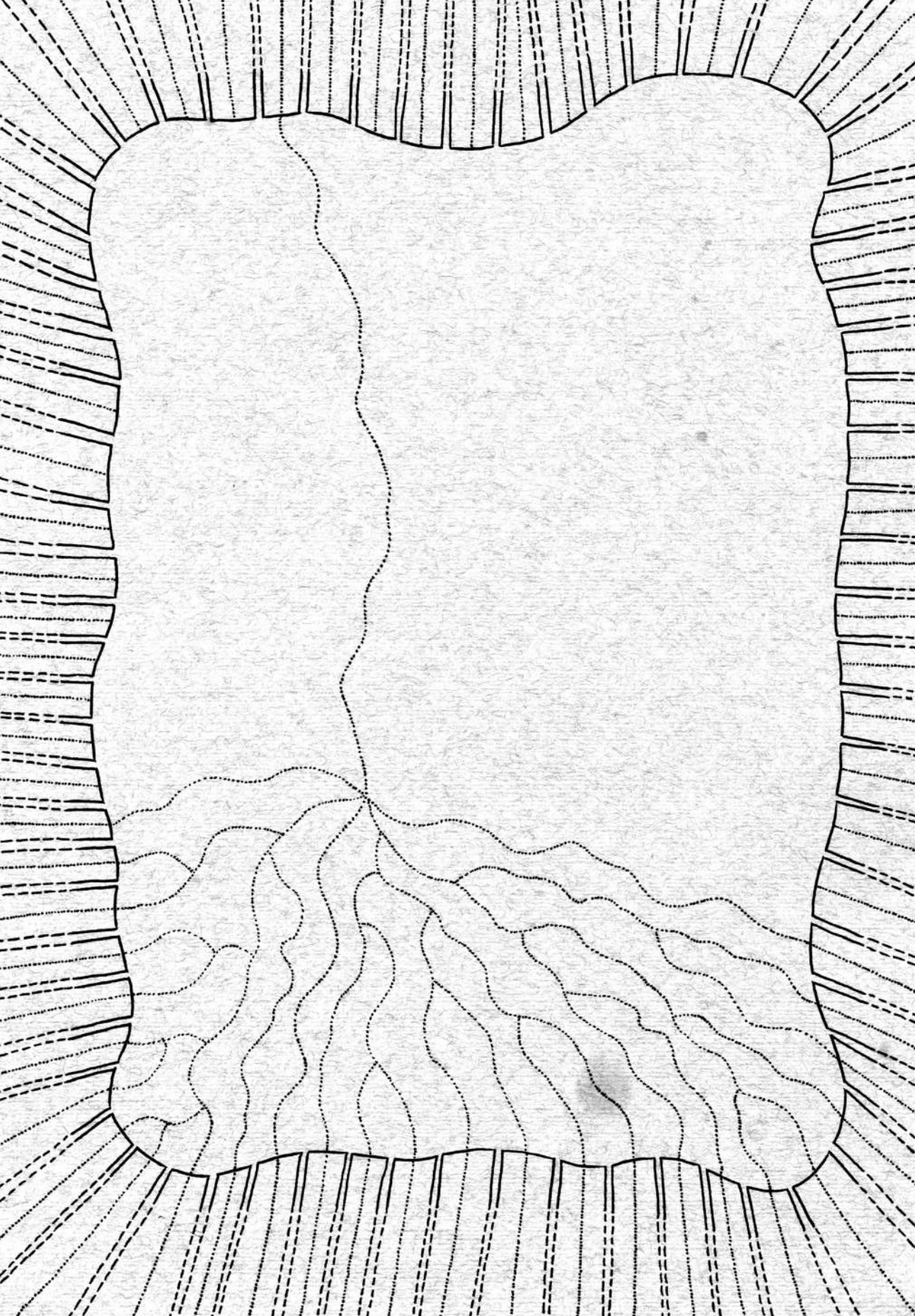
For this reason, “domestic” workshops such as Open Source Estrogen, which are synthesizing pharmaceuticals and sharing this knowhow in open source format, which could be defined as “alien” medical practices in the spirit of “opening the pill”³¹ as well as representing a specific field of “digital social innovation” located between biohacking and open science, are also strongly connected with existing social movements that are demanding more affordable public healthcare systems, where autonomy, self-determination, access to medical data and open source can be guaranteed as rights.

28 – Tsang, Mary. 2017. *Open Source Estrogen: From Biomolecules To Biopolitics... Hormones With Institutional Biopower!* (Doctoral dissertation, Massachusetts Institute of Technology).

29 – Collingwood-Richardson, Kit. 2018. “Empathy and the Future of Policy Making”, *Medium.com*, May 14. <https://medium.com/foreword/empathy-and-the-future-of-policy-making-7d0bf38abc2d> (accessed May 30, 2019).

30 – Bass, Theo and Stokes, Matt. 2018. “Hacking Bureaucracy from the Inside.” *Nesta.org.uk*, June 11. <https://www.nesta.org.uk/blog/hacking-bureaucracy-inside> (accessed May 30, 2019).

31 – Preciado, Paul B. 2019. “La rivolta nell'epoca tecnopatriarcale”, *Kabulmagazine.com*, May 11. <http://www.kabulmagazine.com/paul-b-precियो-rivolta-epoca-tecnopatriarcale> (accessed May 30, 2019).



Caring for the Carers.

Valeria Graziano

The last century accustomed us to consider care and technology as two opposing concepts. We are told that care is about affectivity and empathy, while technology is cold and rational. And yet, as Annemarie Mol explains, all care practices use technological tools.¹ Rather than imagining care as an innate faculty, therefore, we could begin to see it as a set of techniques and skills acquired in relation to the tools at our disposal.

Digital technologies in this sense are opening up many interesting scenarios. Their main promise is to automate the most strenuous or repetitive tasks of care work. In this sense, automation would allow caregivers to focus their attention and expertise on the more relational aspects of the role. Within this field, the specific trend towards open technologies aims to go further in transforming care by trying to respond to care needs that are extremely bespoke (and therefore not interesting enough for the markets) and to free care itself from the market-driven logics of technological innovation altogether.

Many DSI projects embrace such open ethics by focusing on the recipients of the services and their needs. As the slogan by the British innovation foundation Nesta has it, an alternative vision for “People Powered Health”² rightly emphasizes the benefits of redesigning health provisions and services by involving not only patients and their support networks, but also a broader communities of volunteers and other social stakeholders.³

1 – Mol, Annemarie, Ingunn Moser, and Jeannette Pols, eds. 2015. *Care in Practice: On Tinkering in Clinics, Homes and Farms* (Vol. 8). transcript Verlag.

2 – Nesta. 2012. *People Powered Health: Co-Production Catalogue*. London: National Endowment for Science, Technology and the Arts.

3 – See Practices EchOpen, p. 102.

Beyond the enthusiasm for a less top-down conception of care and a more horizontal and active involvement of communities in their welfare services, it is nonetheless crucial to critically address too what the changes envisioned in the DSI approach can entail for all those caregivers who make a living out of their work, operating as professionals rather than on a voluntary basis. Even within some DSI contexts, we note a tendency to avoid tackling the thorny questions connected with care work head on, including the central issue of remuneration: who should pay for care work? And how much?

As Helen Hester put it (borrowing in turn a famous expression by John Naisbitt)⁴, the rapid development and adoption of technological care equipment for remote monitoring, self-diagnosis and other forms of telemedicine risks splitting care work between “high tech” and “high touch” workers⁵: on the one hand, well-paid professionals developing or operating new technologies; on the other, much poorer and much less qualified assistants taking care of the operations that are not easily automatable, such as dressing, lifting or washing patients. The division of care labor is already uneven and racialized and relies on migrant workers, outlining what the sociologist Arlie Hochschild called a “global care chain”⁶, referring to the impressive global network of workers, mostly women, who migrate to care for the elderly, children, disabled and sick persons in rich countries; these workers must in turn be replaced by other carers in their places of origin.

4 – Naisbitt, John, Nana Naisbitt, and Douglas Philips. 2001. *High Tech, High Touch: Technology And Our Accelerated Search For Meaning*. London: N. Brealey.

5 – Richards, Luke. 2017. “Automation and Healthcare: An Interview with Helen Hester”. *Autonomy Interview 2*, Autonomy Research Limited, December. <http://autonomy.work/wp-content/uploads/2018/08/Helen-Hester-Interview-02.pdf> (accessed May 1, 2019).

6 – Hochschild, Arlie Russell. 2000. “Global care chains and emotional surplus value.” *On the Edge: Living with Global Capitalism* 3, no. 5: 130–46.

By solely emphasizing the active role of patients and their informal support networks made up of friends and relatives (ironically, the so-called “dear” ones), we risk neglecting the problem of daily care work conceived as a private problem, as Melinda Cooper pointed out, avoiding the question of who is called to do it under such informal arrangements and under what conditions.⁷ Free work thus risks returning (or continuing?) to be an implicit asset of the reorganization of care in the post-digital era.

The “dear” ones invoked alongside the empowered patients actually risk re-proposing a family-based model of care fundamentally organized according to coercive principles and mostly impacting women. Avoiding the issue of the remuneration of care work also risks neglecting the toll it takes on the caregivers, who can fall ill in turn. In the book *Forced To Care*, Evelyn Nakano Glenn highlighted how:

*Many studies have documented high stress levels among family members who provide intensive care or who combine work and care for parents and disabled spouses and children. The demands of intensive care leave caregivers with little time or energy to look after their own wellbeing, so that their own health suffers. Numerous studies have shown that caregivers experience higher rates of heart disease, high blood pressure, diabetes, and depression. Other studies have documented the detrimental economic effects of caring for elderly or disabled family members.*⁸

7 – Cooper, Melinda. 2017. *Family Values: Between Neoliberalism and the New Social Conservatism*. Cambridge, Mass: MIT Press.

8 – Glenn, Evelyn Nakano. 2012. *Forced to Care: Coercion and Caregiving in America*. Cambridge, Mass: Harvard University Press, 3.

Taking care of the caregivers

What would it mean instead to rethink the theme of care work in the light of the profound changes connected to its deeper technologization? In large part, the reactionary vision of the role of the family and of women in care, but also, in another sense, the outsourcing of care work as a service entrusted to categories of contractually weak workers, are problems that can only be tackled through far-reaching political processes. A central one would be the questioning of work itself as the main social mechanism for the redistribution of wealth, in favor of an unconditional universal basic income.⁹

However, here I want to explore two emerging aspects linked to the mutations of care and the possibilities supported by open technologies conceived from the workers’ point of view. These concern both the possibility of overcoming the Fordist organization of personal services and the need to extend the ethics of care to the technological objects that support it.

Self-management as a social technology: Buurtzorg nurses

One of the obsessions of contemporary management is the use digital technologies for monitoring the performance of employees in real time. While in Ford’s times, efficiency in production had become synonymous with the division of labor into increasingly simplified and abstract tasks, to be repeated ever more rapidly, nowadays digital management systems such as apps, badges and wearable trackers of all kinds have created an invisible but absolutely concrete control infrastructure for

9 – See for instance Basic Income Network Italia: www.bin-italia.org/

workers. In contrast, DSI could potentially be used to overcome the Fordist model of work within the care sector. The example of the nurses of the Buurtzorg association in the Netherlands shows that better results can be achieved when care is managed as independently as possible directly by those who dispense it.



Buurtzorg is a non-profit organization of neighborhood nurses founded in 2006 by Jos de Blok. Neighborhood nurses have been a specific professional figure in the Dutch healthcare system since the last century, acting as a link between hospitals, primary care physicians and patients visited at home. Since the 1990s, however, the role of the neighborhood nurse has been outsourced, along with many others, so that the nurses have had to establish themselves in autonomous sub-contracting organizations bidding for tenders with the public sector. Until the advent of Buurtzorg, the management of these organizations followed a classical organizational logic, based on competitiveness and efficiency: typically, the nurses' shifts would be planned centrally by a manager and then distributed daily to save time on the distance between appointments; nurses would use a badge to track the tasks performed with each patient, and each of these

tasks would be pre-allocated a given amount of time (10 minutes for giving someone an injection, 15 for giving a bath, and so on).¹⁰ Furthermore, the tasks would usually be assigned according to the different levels of expertise of the caregivers, so that the most qualified (and therefore most expensive) nurses would find themselves managing only the most difficult interventions, while the less qualified ones would struggle to make progress.

This Fordist approach to home care (powered by technology) has produced very poor results. Not only do patients complain about the lack of a personal relationship with their nurses, who change constantly, but they get sick more frequently. The nurses also declare that they feel devalued in their professional competence in this mainstream managerial regime.

The birth of Buurtzorg revolutionized this system, proposing an organizational model inspired by totally different principles from monitoring, efficiency and standardization. While it does use coordination technologies, Buurtzorg has totally eliminated the figure of the manager. Here the nurses manage themselves in teams of 10–12 people. The whole team takes care of all the tasks, avoiding the fragmentation of the services offered. The teams also have full autonomy to decide on issues regarding shifts, holidays, and possible collaborations with rehabilitation centers or pharmacies. The performance of the activities is monitored and discussed within the nurses' assembly, and there is no one who evaluates it from above.

Furthermore, the staff of Buurtzorg promote an approach that supports a maximum decision-making

¹⁰ –Laloux, Frédéric, and Etienne Appert. 2016. *Reinventing Organizations: An Illustrated Invitation to Join the Conversation on Next-Stage Organizations*. Millis: Parker Nelson, 62–73.

autonomy for their patients, too, whom the nurses come to know in depth, because they have the time to stop and talk to them, to listen to their needs and those of their family members.

All this does not mean, of course, that conflicts do not occur or that difficulties do not arise. However, Buurtzorg supports nurses with specific training courses on subjects such as self-management and conflict mediation techniques. When a delicate situation requires it, figures with specific competences, such as expert coaches and expert nurses, offer teams support to resolve specific problems, although they have no decision-making or disciplinary powers.

The results of this different organization of care work are impressive. A 2009 study by Ernst & Young found that Buurtzorg requires on average 40% fewer hours of care compared to delivery through traditionally managed organizations. Patients remain in care for less time, and tend to have fewer relapses. Calculated in economic terms, the Buurtzorg approach saves the Dutch healthcare system about €60 million a year. Perhaps this is the main reason why the Buurtzorg model is currently being tested in nine other countries. To those who ask their founder if he intends to patent Buurtzorg and make a franchise, De Blok replied that he would rather prefer to see his model adapted to different contexts. “I’m not interested in money,” he commented in a recent interview for *The Guardian*. “I see so many people searching for a new way of doing things in all the places I visit. It’s all about creating something different from the bottom up”.¹¹

11 – Brindle, David. 2017. “Buurtzorg: the Dutch Model of Neighbourhood Care that is Going Global”, *The Guardian*, May 9. <https://www.theguardian.com/social-care-network/2017/may/09/buurtzorg-dutch-model-neighbourhood-care> (accessed May 30, 2019).

What remains more difficult to measure, as perhaps it should, is the impact of this approach on the personal wellbeing of the workers involved.

However, recent figures provide indicators: the staff turnover at Buurtzorg is 33% less than in other organizations and, just like their patients, the nurses who work there get sick 60% less than the others. It turns out that the organization of care labor can be a technology of care in its own right.¹²

The approach to self-management and training developed by Buurtzorg (open and non-patented, in line with the DSI principles) foreshadows an ideal use of digital technologies in the healthcare sector, recasting the role of open technologies as tools for enhancing the capacity for coordination, autonomy and self-determination of workers and patients alike. Rather than harassing workers through the proliferation of intermediate managerial figures, the imposition of assembly-line work practices and continuous monitoring, the role of shared self-management technology in care processes could be re-designed, for example, through the creation of online cooperative platforms run by the workers themselves, replacing the many temping agencies in the sector.

... but what about non-human caregivers?

The DSI approach has a role in the ongoing transformations of an aspect of care which is perhaps more hidden, but no less essential: the maintenance and repair of technological objects used in treatment itself. The orientations of contemporary medicine point

12 – The links between workers well-being and forms of autonomous organizations are already well known; see, for instance, the experience of institutional analysis in France and the experiences of workers’ self-management in Yugoslavia.

towards a future in which the body will become more and more intimate (not only outside, but also inside) with technological objects of various types, ranging from surgical meshes to cardiac defibrillators or deep brain stimulators. There are devices that connect the body to the network (such as pressure-monitoring clocks), those that administer drugs, and those that combine digital aspects with biological



components, such as the subcutaneous microsensors used by diabetics. Moreover, high-precision digital instruments are becoming increasingly indispensable tools in diagnosis and surgery.

In all these cases, caregiving and curing becomes, just as Mol suggested, the result of an ever deeper interweaving of human competences and the performance of technological objects, which someone will have to ensure remain in an effective and functioning state. So who and how should take care of the care machines? And under what conditions?

Although machinery has become an integral part of medicine since the 1970s and has a huge impact on treatment costs, laws governing the lifecycle of medical equipment have struggled to keep pace with the ongoing changes. In the United States (whose laws often influence the legal approaches

internationally), legislators have not yet come to develop a normative framework that clearly assigns responsibility for the maintenance and repair of the technologies implanted in the body, a situation that some researchers have denounced as alarming.¹³ Yet complex devices such as surgical robots or 3D body scanners require specialized engineers and technicians who are not always easily available in hospitals. The growing intimacy between technology and the body requires extending the ethics of care to objects, because if even a simple common defibrillator is of no use if it is broken, we can well imagine that the complications that a malfunctioning pacemaker can have are of a completely different order.

Maintaining and repairing such technologies is often difficult, lengthy and costly for users due to manufacturers' desire to maintain total control over the products. Third-party technicians are denied information, problems are artificially made difficult to diagnose, and monopolies over spare parts are maintained.

This is a little-known limitation, but one that greatly impacts the capacity for intervention and care of hospitals with low budgets. In poorer countries and regions, the issue of broken or malfunctioning medical devices often has serious, life-or-death consequences for people. The data provided by the World Health Organization is discouraging: in some countries, 50% of medical machinery is unusable at any given time; in some cases, this figure is as high as 80%.¹⁴

13 – Davies, Dave. 2018. "Are Implanted Medical Devices Creating a 'Danger Within Us'?" *NPR.org*, January 17. <https://www.npr.org/2018/01/17/578562873/are-implanted-medical-devices-creating-a-danger-within-us> (accessed May 30, 2019).

14 – The Repair Association, "Device Companies are Cutting Hospitals Out of the Loop", *Repair.org*, <https://repair.org/medical> (accessed May 30, 2019).

Here, the care work of repairers and medical personnel in support of collective well-being clashes very clearly with the interests of a small number of powerful private businesses. Alongside organized legal battles for the right to repair (such as the one carried forward by the Repair Association in the United States), some technicians have chosen to react to the situation with bottom-up initiatives. This is the case with Mike, the retired biomedical technician who runs The Electric Squirrel site,¹⁵ which is dedicated to the maintenance of the most common technical equipment in use across the southern hemisphere. It also applies to Frank Weithoener, another technician specializing in biomedical machinery, based in Tanzania. Frank, who has worked as an instructor and consultant in several so-called “developing” countries, claims to have opened his site because he was tired of meeting absurd obstacles to repairs everywhere he went.

On his website Frank’s Hospital Workshop,¹⁶ he collects and publishes all the maintenance and technical documentation manuals he can get his hands on, as well as providing his own tutorials. As expected, manufacturing companies such as Weyer, General Electric and others regularly threaten to sue Frank, telling him to take the manuals offline.¹⁷ But fortunately he has thus far resisted pressure and continued in his mission: to take care of the machines we need to cure ourselves.

The barriers to maintenance identified by Frank are many and diverse: not only the difficulty in finding

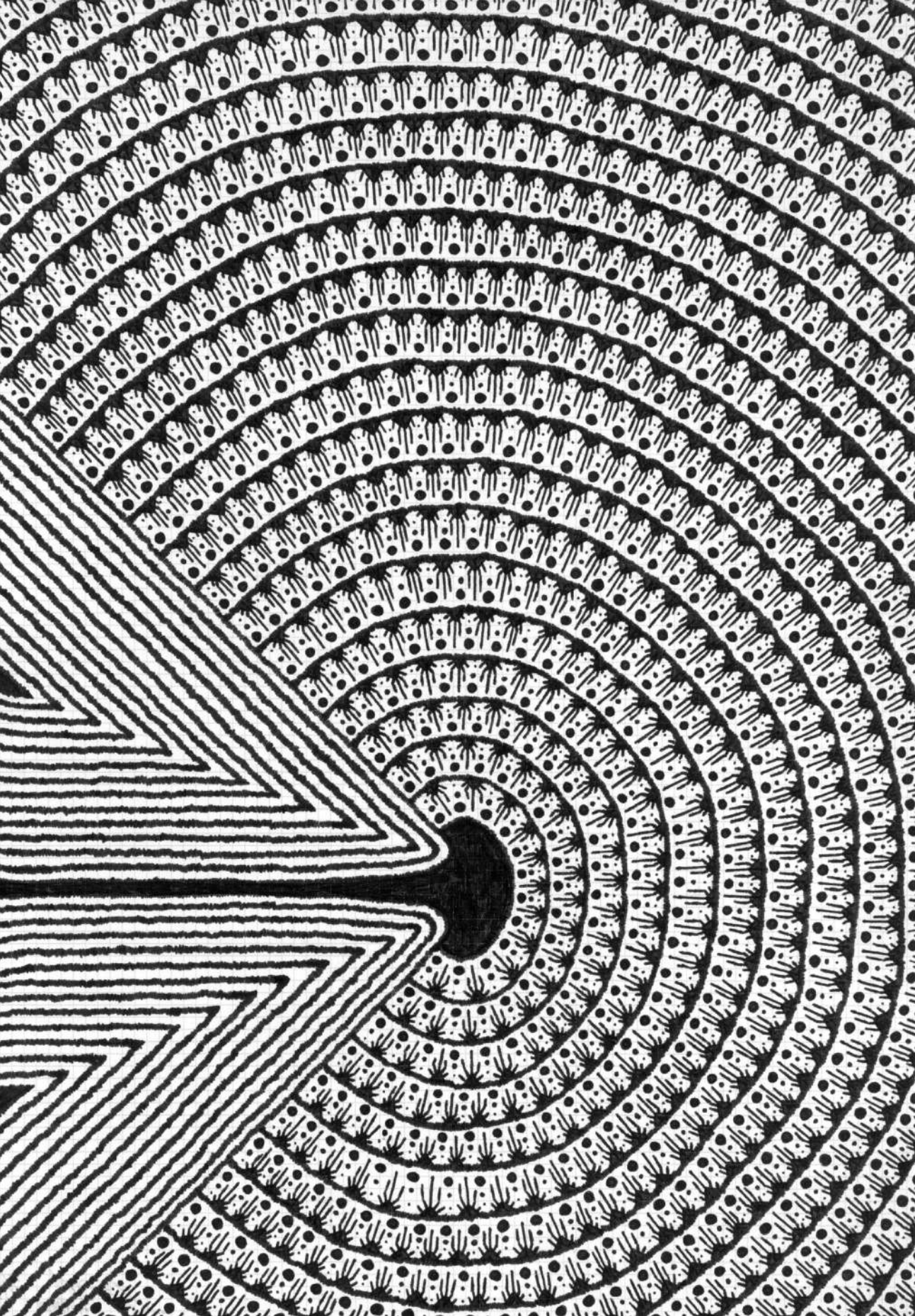
spare parts, because the parent companies maintain their monopolies, but also the lack of attention from policymakers for financing technical support and allocating specific funds for preventive maintenance of equipment and the continuous training of technicians. This neglect highlights a clear continuity with an older trend: the instrumental invisibility attributed to more traditionally understood “care work”.

We could then start from here to draw the contours of a different approach to care work, one which requires a joint reflection around its technologies and the reorganization of living labor, going beyond a mere techno-solutionist approach by insisting on the conditions under which the caring for human and non-human caregivers can take place in the best possible way.

15 – The Electric Squirrel. “Introduction.” [https:// theelectricsquirrel.wordpress.com](https://theelectricsquirrel.wordpress.com) (accessed May 30, 2019).

16 – Frank’s Hospital Workshop. <http://www.frankshospitalworkshop.com> (accessed May 30, 2019).

17 – The Repair Association, “Device Companies are Cutting Hospitals Out of the Loop”, Repair.org, <https://repair.org/medical> (accessed May 30, 2019).



Pirate Care.

Valeria Graziano

A recent trend to reimagine the systems of care for the future as based on many of the principles of self-organization. From the passive figure of the patient—a subject who suffers and needs aid from medical staff and carers—researchers and policymakers are moving towards a model defined as people-powered health—where care is discussed as transforming from top-down service into a network of coordinated actors.

At the same time, for large numbers of people, to self-organize around their own healthcare needs is not a matter of predilection, but increasingly one of necessity.

In Greece, where the measures imposed by the Troika have decimated public services, a growing number of grassroots clinics set up by the Solidarity Movement¹ have been providing medical attention to those without private insurance. In Italy, initiatives such as the Ambulatorio Medico Popolare² in Milan offer free consultations to migrants and other vulnerable citizens.

The new characteristic of all of these cases is the fact that they frame what they do in clearly political terms, rejecting or sidestepping the ways in which the third sector and NGOs have long presented care practices as apolitical, as ways to help out that should never ask questions bigger than the problems they set out to confront, and as standing beyond left and right (often for the sake of not alienating potential donors and funders).

Rather, the current trends towards self-organization in health care are very vocal and clear in their message: the care system is in crisis, and we need to learn from what

we know already. One thing we know is that the market or the financialization of assets cannot be the solution. (Do you remember when just a few years ago Occupy³ was buying back healthcare debts from financial speculators, thus saving thousands of Americans from dire economic circumstances? Or that scene from Michael Moore's *Sicko*⁴, the documentary where a guy has to choose which finger to have amputated because he does not have enough money to save both?).

Another thing we also know is that we cannot simply hold onto past models of managing the public sector, as most national healthcare systems were built for the needs of the last century. Administrations have been struggling to adapt to the changing nature of health conditions (moving from a predominance of epidemic diseases to a predominance of chronic conditions) and the different needs of today's populations. And finally, we most definitely know that to go back to even more conservative ideas that frame care as a private issue that should fall on the shoulders of family members (and most often, of female relatives) or hired servants (also gendered and racialized) is not the best we can come up with.

Among the many initiatives that are rethinking how we organize the provision of health and care in ways that are accessible, fair and efficient, there are a number of actors—mostly small organizations—who are experimenting with the opportunities introduced by digital technologies.

While many charities and NGOs remain largely ignorant of the opportunities offered by technology, these new actors are developing DIY devices, wearables, 3D-printed bespoke components, apps and smart objects to intervene

1 – Green Solidarity Campaign, “About us”, *Greensolidarity.org*, http://greesolidarity.org/?page_id=2 (accessed May 30, 2019)

2 – Bin Italia, “Ambulatorio Medico Popolare di Milano”, *Commonfare.net*, <https://commonfare.net/it/stories/ambulatorio-medico-popolare> (accessed May 30, 2019).

3 – Crimp, Douglas. 2011. “Before Occupy: How AIDS Activists Seized Control of the FDA in 1988”. *The Atlantic*, December 6. <https://www.theatlantic.com/health/archive/2011/12/before-occupy-how-aids-activists-seized-control-of-the-fda-in-1988/249302/> (accessed May 1, 2019).

4 – *Sicko*. Directed by Michael Moore. New York, NY: dog eat dog films, 2007.

in areas otherwise neglected by the bigger players in the care system. These practices present a new mode of operating that I want to call “pirate care”.

Pirate Care

Piracy and care are not always immediately relatable notions. The figure of the pirate in popular and media cultures is often associated with cunning intelligence and masculine modes of action, of people running servers allowing people to illegally download music or movie files. One of the very first organizations that articulated the stakes in sharing knowledge was actually named Piratbyrå⁵. “When you pirate mp3s, you are downloading communism,” was a popular slogan at the time.

And yet, giving the idea of a pirate ethics a resonance with contemporary modes of care invites a different consideration for practices that propose a paradigm change and therefore inevitably position themselves in tricky positions vis-à-vis the law and the status quo.

I have been noticing for a while now that another kind of contemporary pirate is coming to the fore in our messy society with its many crises. This new kind of pirate could be best captured by another image: this time it is a woman, standing on the dock of a boat sailing through the Caribbean Sea towards the Mexican Gulf, about to deliver abortion pills to other women for whom this option is illegal in their country.

Women on Waves⁶, founded in 1999, engages in its abortion-on-boat missions every couple of years.

5 – Piratbyrå, Piratbyran.org, (accessed May 30, 2019).

6 – See Practices Women on Waves, p. 98.

They are mostly symbolic actions, as they are rather expensive operations, and yet they are potent means for stirring public debate and have often been met with hostility—even military fleets. So far, they have visited seven countries so far, including Mexico, Guatemala and, more recently, Ireland and Poland, where feminists movements have been mobilizing in huge numbers to reclaim reproductive rights. According to official statistics, more than 47,000 women die every year from complications resulting from illegal and unsafe abortion procedures, a service used by over 21 million women who do not have another choice. As Leticia Zenevich, spokesperson for Women on Waves, told HuffPost: “The fact that women need to leave the state sovereignty to retain their own sovereignty makes it clear states are deliberately stopping women from accessing their human right to health.”⁷

Besides the boat campaigns, the organization also runs Women on Web, an online medical abortion service active since 2005. The service is active in 17 languages, and helps more than 100,000 women per year get information and access abortion pills. More recently, Women on Waves also begun experimenting with the use of drones to deliver the pills in countries impacted by restrictive laws (such as Poland in 2015 and Northern Ireland in 2016).

Women on Waves are the perfect figure to begin to illustrate my idea of “pirate care”. By this term I want to focus attention on an emerging phenomenon in the contemporary world, where more and more often initiatives that aim to bring support and care to the most vulnerable in the most unstable situations increasingly have to operate in the grey zone that exists in the gaps left open by rules, laws and technologies.

7 – Ruiz-Grossman, Sarah. 2017. “This Boat Sails Women Into International Waters To Give Abortions.” *Huffington Post UK*, May 5. https://www.huffingtonpost.co.uk/entry/women-on-waves-abortion-boat_n_590b8338e4b0d5d9049a857c (accessed October 5, 2018).

Some thrive in this shadow area, carefully avoiding calling attention to themselves for fear of attracting ferocious polemics and the trolling that inevitably accompanies them. In other cases, care practices that were previously considered the norm have now been pushed towards illegality.

Consider, for instance, the situation highlighted by the Docs Not Cops⁸ campaign, which started in the UK four years ago, when the government had just introduced its “hostile environment” policy with the aim of making everyday life as hard as possible for migrants with an irregular status. Suddenly, medical staff in hospitals and other care facilities were supposed to carry out document checks before being allowed to offer any assistance. The medical staff mobilization denounced the policy as an abuse of mandate by the Home Office and a threat to public health, given that it effectively discouraged patients from seeking help for fear of retaliation.

Another sadly famous example of this trend of pushing many acts of care towards illegality would be the straitjacketing and criminalization of migrant-rescuing NGOs⁹ in the Mediterranean on the part of various European countries, a policy led by Italian government. Yet another example would be the increasing number of municipal decrees that make it a crime to offer food, money or shelter to the homeless in many cities in North America¹⁰ and Europe.

8 – Docs not cops, www.docsnocops.co.uk (accessed May 30, 2019).

9 – De Bellis, Matteo. 2018. “How Italy’s seizure of an NGO ship exposes Europe’s dangerous policy”, *Amnesty.org*, March 29. <https://www.amnesty.org/en/latest/news/2018/03/how-italys-seizure-of-an-ngo-ship-exposes-europes-dangerous-policy> (accessed May 30, 2019).

10 – Guarnieri, Grace. 2017. “Why it is illegal to feed the homeless in cities across America”, *Newsweek.com*, December 2017. <https://www.newsweek.com/illegal-feed-criminalizing-homeless-america-782861> (accessed May 30, 2019).

Hacker Ethics

This scenario reminds us of the tragic story of Antigone and the age-old question of what to do when the relationship between what the law says and one what feels is just becomes fraught with tensions and contradictions. Here, the second meaning of “pirate care” becomes apparent as it points to the way in which a number of initiatives have been responding to the current crisis by mobilizing the tactics and ethics first used within the hacker movement.

As described by Steven Levy in *Hackers: Heroes of the Computer Revolution*¹¹, the general principles of a hacker ethic include sharing, openness, decentralization, free access to knowledge and tools, and an effort of contribute to society’s democratic wellbeing. To which we could add, following Richard Stallman, the founder of the free software movement, that “bureaucracy should not be allowed to get in the way of doing anything useful”.¹² While Stallman was reflecting on the experience of the M.I.T. AI Lab in 1971, his critique of bureaucracy captures a specific trait of the techno-political nexus that is also shaping the present moment: as more technologies come to mediate everyday interactions, they are also reshaping the very structure of the institutions and organizations we inhabit, so that our lives are increasingly formatted to meet the requirements of an unprecedented number of standardized procedures, compulsory protocols and legal obligations.

11 – Levy, Steven. 1974. *Hackers: Heroes of the Computer Revolution*. Garden City, NY: Anchor Press/Doubleday.

12 – Stallman, Richard. Quoted in Schell, Bernadette H., and John L. Dodge. 2002. *The Hacking of America: Who’s Doing it, Why, and How*. Greenwood Publishing, 45.

According to the anthropologist David Graeber, we are living in an era of “total bureaucratization”.¹³ But while contemporary populism often presents bureaucracy as a problem of the public sector, implicitly suggesting “the market” to be the solution, Graeber’s study highlights how historically all so-called “free markets” have actually been made possible through the strict enforcement of state regulations.

Since the birth of the modern corporation in 19th-century America, “bureaucratic techniques (performance reviews, focus groups, time allocation surveys, etc.) developed in financial and corporate circles came to invade the rest of society—education, science, government—and eventually, to pervade almost every aspect of everyday life”.¹⁴

The forceps and the speculum

And thus, resonating with the tradition of hacker ethics, a number of “pirate care” practices are intervening to reshape what looking after our collective health will look like in the future. CADUS¹⁵, for example, is a Berlin-based NGO which has recently set up a Crisis Response Makerspace to build open and affordable medical equipment specifically designed to bring assistance in extreme crisis zones where few other organizations would venture, such as Syria and northern Iraq.

13 – Graeber, David. 2015. *The Utopia of Rules: On Technology, Stupidity, and the Secret Joys of Bureaucracy*. Melville House Publishing. Ebook.

14 – *Ibid.*

15 – Cadus e.V., “Crisis Response Makerspace”, Cadus.org, <https://cadus.org/en/projects/project/crisis-response-makerspace-451> (accessed May 30, 2019).

After donating their first mobile hospital to the Kurdish Red Crescent last year, CADUS is now working to develop a second version, in a container this time, which is able to be deployed in conflict zones deprived of any infrastructure, and a civil airdrop system to deliver food and medical equipment as quickly as possible. The fact that CADUS adopted the formula of the makerspace to invent open emergency solutions that no private company would be interested in developing is not a coincidence, but emerges from a precise vision of how healthcare innovations should be produced and disseminated, and not only for extreme situations.

“Open source is the only way for medicine”—says Marcus Baw of Open Health Hub—as “medical software now is medicine”.¹⁶ Baw has been involved in another example of “pirate care” in the UK, founding a number of initiatives to promote the adoption of open standards, open source code and open governance in Health IT.

The UK NHS spends about £500 million each time it refreshes its Windows licenses, and aside from avoiding the high costs, an open-source GP clinical system would be the only way to address a pressing ethical issue facing contemporary medicine:

16 – Baw, Marcus. 2018. “Open source is the Only Way for Medicine.” *Medium.com*, June 19. https://medium.com/@marcus_baw/open-source-is-the-only-way-for-medicine-9e698de0447e (accessed September 3, 2018).

As software and technology become more and more part of the practice of medicine itself, they need to be subject to peer-review and scrutiny to assess their clinical safety.

Moreover, that if such solutions are found to be effective and safe lives, it is the duty of all healthcare practitioners to share their knowledge with the rest of humanity, in accordance with the Hippocratic Oath. To illustrate what happens when medical innovations are kept secret, Baw shares the story of the Chamberlen family of obstetricians, who kept the invention of the obstetric forceps a family trade secret for over 150 years, using the tool only to treat their elite clientele of royals and aristocracy. As a result, thousands of mothers and babies likely died in preventable circumstances.

It is perhaps significant that such a sad historical example of the consequences of closed medicine must come from the field of gynecology, one of the most politically charged areas of medical specialization to this day. This is so much so that last year another collective of “pirate carers” named GynePunk¹⁷ developed a biolab toolkit for emergency gynecological care, to allow those excluded from the reproductive healthcare—undocumented migrants, trans and queer women, drug users and sex workers—to perform basic checks on their own bodily fluids.

Their prototypes include a centrifuge, a microscope and an incubator that can be created cheaply by repurposing components of everyday items such as DVD players and computer fans, or by digital fabrication. In 2015, GynePunk also developed a

3D-printable speculum¹⁸ Perhaps their next project might include a pair of forceps...

As the “pirate care” approach proliferates more and more, its tools and modes of organizing are keeping alive a horizon in which healthcare is not de facto reduced to a privilege.

¹⁷ – Chardronnet, Ewen. 2015. “GynePunk, the cyborg witches of DIY gynecology”, Makersy.info, June 30. www.makersy.info/en/2015/06/30/gynepunk-les-sorci%C3%A9res-cyborg-de-la-gyn%C3%A9cologie-diy/ (accessed May 30, 2019).

¹⁸ – Gaudi, “GynePunk Speculum”, Thingiverse.com, <https://www.thingiverse.com/thing:865593> (accessed May 30, 2019).

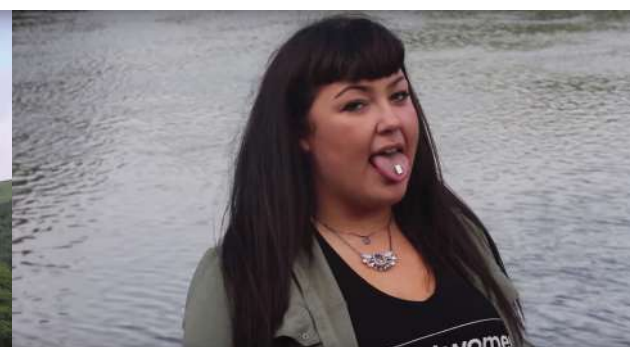
Seven practices.



Abortion Drone

www.womenonwaves.org

The Abortion Drone project of the NGO Women on Waves is an activist communication campaign promoting the right to abortion.



The project uses drones to transport abortion pills from one country to another, overcoming both geographical boundaries and legislative limits, highlighting the condition of women living in those countries where there is a restrictive regulation on accessing safe abortion (up to the ninth week).

The drone was used on June 2, 2016 for to transport abortion pills from the Republic of Ireland to Narrow Waters Castle in Northern Ireland. Once landed, the pills were collected by two activists on the ground, while a fast boat carried a greater load of pills.

The drugs carried by the drone are Mifepristone and the Misoprostol, which included in the list of essential medicines defined by the World Health Organization in 2005. Having access to and using this type of essential medicine is recognized as a right in many international agreements. The UN Human Rights Commission declared the Republic of Ireland's abortion law a violation of human rights. Until recently, in fact, Irish women were forced to cross borders and travel to countries where this right is respected.

Finally, in 2018, thanks to a referendum, over 66% of voters expressed their opinion to abolish the amendment of the constitution that in 1983 had banned abortion, punishing it with up to 14 years' imprisonment.

In Northern Ireland, however, abortion is still illegal and the maximum penalty for administering drugs that induce it is, according to the Offences against the Person Act 1861, a life sentence.

The action of the Abortion Drone in Ireland is the result of a collaboration between three organizations involved in women's rights: Labor Alternative, a minority political party, the Rosa group (Reproductive rights, against Oppression, Sexism & Austerity) both of Northern Ireland, and Women on Waves, which also replicated the initiative on the border between Germany and Poland. In the opinion of the organizers, during these demonstrative actions, no law was broken. Certainly, it serves to show how different life is for Irish and Polish women compared to those living in other European countries and, above all, to provoke a debate that, in the case of the Republic of Ireland, has favored change.

OpenRampette

www.rampette.opencare.cc

OpenRampette is a pilot initiative to improve the accessibility of shops in the city of Milan for those who need to have access via a ramp or slide.



The story begins in 2015 when the city of Milan passed a Building Regulation that required all bars, shops, restaurants and craft activities bordering a road to provide easy access to people with limited mobility or disabilities. This normative action was the instrument that Milan deployed to overcome architectural barriers and provide universal free access to public places. Twelve months after the law was passed, Milan assessed that a small percentage of businesses was compliant with the norm. Local staff including WeMake makerspace was involved and started activating a co-design process, to understand what was not working and put it right.

The team brought together shopkeepers, makers and people with disabilities which identified, co-designed and implemented low-cost solutions to allow and improve accessibility to commercial activities of the area. The experimental project started with planning meetings which revealed the emergence of two obstacles: the complex procedure for the setting in compliance of the shops; and the lack of clarity about how people could call and visit a shop and use a mobile ramp.

WeMake therefore co-designed a step-by-step support that serves as a guide to compiling documents to communicate and validate the presence of the mobile ramp with the city authorities in Milan. A mini-website was prototyped to facilitate the data-submission to the public office by the shop. Through digital fabrication and open source technologies, the team co-designed a visible but protected device to be positioned outside of the shop and make it more visible with a sticker.

Together with the device, they also implemented a doorbell receiver to notify the shopkeeper with light, sound or vibration for the assistance request. The device was coupled with a smartphone app designed to notify the person with motor disabilities whenever they were near an accessible store and making it possible to request assistance, by ringing the bell, via smartphone.

The project took place within EU-funded project Opencare in a collaboration with WeMake makerspace and the Municipality of Milan.

EchOpen, an open source echo-stethoscope, involves a group of experts and a large online community to develop a low-cost solution to diagnostic orientation in hospitals.



EchOpen began in 2015 with the aim to tackle a series of issues related to the design of medical devices for diagnostics using ultrasound technology. Ultrasound technology is usually embedded in large equipment that requires patients to be moved around, and is usually very expensive and beyond the means of hospitals in developing countries. Furthermore, it requires qualified paramedics to analyze the results and is proprietary technology, so it cannot be fixed easily by technicians.

The project tries to radically transform diagnostic orientation with an open-source device, a universal ultra-portable ultrasound imaging or medical visualization tool intended to accompany health professionals in the clinical practice of diagnostic orientation. The echo-stethoscope primarily helps physicians who have never taken ultrasound images and who have taken a 48-hour training program to master the concept.

Today, diagnostics require a long period of training because doctors use traditional stethoscopes, but EchOpen allows a quick diagnosis

as the results are visualized in real time through the mobile device. Alternatively, paramedics in remote areas can send the data via the web to receive feedback from doctors remotely. The project is currently an assembled functional prototype, tested with a community of doctors and developed by the core team together with legal advisors, hardware experts and designers. The core team consists of around 10 people, while the larger development team includes about 30 people. The online community numbers some 500 people.

An online guide provides guidelines on how to contribute to the project, how to participate in the several subgroups within the community, and how to set up a hardware lab with tools to build the device and run tests.

The project has been funded through grants from non-profit organizations, such as the Fondation Pierre Fabre, which supported the first phase of the project in 2015, and partner organizations, which finance the activity of the core team.

Mirrorable

www.fightthestroke.org

An interactive platform featuring an innovative rehabilitation model for young stroke survivors.



The story of Fight the Stroke started when in 2011, Roberto and Francesca's son, Mario, was diagnosed with perinatal stroke at just 10 days old. As parents interested in understanding more, they wanted to find a suitable solution for their son, but were unable to find anything in the market that was useful for early detection, diagnosis, rehabilitation or even simply support for the family. Therefore, they established an association with the aim to leverage the use of scientific research and technology and offer new products and solutions for families experiencing the same situation.¹

Mirrorable, the organization's flagship project, is based on the concept of rehabilitation through the stimulation of mirror neurons, a particular class of neurons that activate both when we accomplish a certain action and when we observe someone doing the same action. The idea is to show a child how to perform certain actions, such as grabbing a pencil, and even though the child is not able to actually

grab it, s/he is stimulated to exercise the cells in the damaged part of the brain.

This new model saves time, effort and resources for families and children going through rehabilitation because is accessible directly at home. Secondly, and most importantly, the model is designed so that the exercises do not seem like rehabilitation sessions. Thirdly, the platform contains a peer education approach which allows children and families to connect with other families to practice together.

To be scientifically validated, the Mirrorable team ran a clinical trial in December 2017. They recruited more than 50 children and families and tested the platform for a few months. Through the pilot stage, they were able to demonstrate that their solution was more effective than traditional methods because the pilot generated a 100% compliance rate.

The organization Fight the Stroke is now a social enterprise aiming to raise capital, especially from the impact-investing sector, leveraging on the fact that they are an organization fulfilling a concrete social need through the use of technology and the interweaving of communities.

¹ – Around the world about 17 million children have had a diagnosis of Infantile Cerebral Palsy.

Soprasotto is an independent kindergarten whose educational and organizational model is co-created by parents to respond to the crisis in the welfare model.

The main features of this permanent lab are: the self-organization and mutual training of all the parents; the schedule's flexibility and the opening up of the kindergarten space to the outside world; the development of strong relationships with the neighborhood; and the idea of food as an educational resource.

Soprasotto's approach to childcare works thanks to its micro and locally rooted dimension. The project is based on the concept



Soprasotto is a permanent laboratory for young children in the nursery age range. This project was created by a group of parents who worked together to develop an educational model able to take into account the transformation of work and its schedules, the changes of roles within families, and the new forms of sociability and cooperation generated in the face of the deep crisis in the welfare model, as well as considering the local neighborhood as a network of resources and social exchanges.

Soprasotto was started in Milan in 2013 as an active response to the lack of available places in public nurseries, a widespread problem in Italy, especially in big cities. Soprasotto is a kindergarten for about 12 children managed through a monthly assembly of parents, which takes care of the different organizational aspects and of the teaching activities for the children, in agreement with the educators. Within the space of the assembly, the dialogue among parents creates a continuous exchange around parenting challenges, activating moments of mutual growth and support around the delicate challenges of early childhood.

that a place designed for children should also be designed for their parents, so that it can accommodate all the challenges of contemporary parenting. The many emails and requests for exchange that this lab received from all over Italy within a few years of activity demonstrate that Soprasotto could become a replicable model, one adaptable to the different regions in which it might be activated.

In 2019 the project released the toolkit "How to open a pirate kindergarten in your neighborhood". Starting from this specific experience of Soprasotto, the booklet shows how to build a space for the collective care of young children. Among other things, the toolkit includes the instructions and complete files on how to build open-source modular furniture for the nursery with the support of local makerspaces, so any space can be easily transformed into a welcoming kindergarten.

Wheelmap.org is a collaborative, online map for finding and pointing out wheelchair accessible places worldwide.



The project is tackling the need of millions of people using wheelchairs, walking aids or carriages when they encounter barriers on their way. Wheelmap is accessible through an app released in 25 languages and allows people to know if a place is wheelchair-accessible or not. Moreover, if you are a registered user you can add pins, provide information about new locations and give every place two different ratings: one for the general accessibility, which answers the question of whether there are steps at the entrance or steps inside; and one for the accessibility of the restrooms, for which there are a few more criteria if they are to be considered suitable for a wheelchair user.

Developed in 2010 by the German non-profit organization Sozialhelden, Wheelmap every day collects around 300 new entries and recently reached 1.6 million pins in more than 150 countries. In order to improve and foster the growth of updated info, Wheelmap promotes initiatives such as “MapMyDay”, a campaign used for organizing mapping events around the world, during which new places are marked on Wheelmap. People and collectives can be part

of this campaign, creating a local mapping event, inviting citizens to explore public places in different cities or towns, and adding them to the crowdsourced database.

In 2018, FedEx gave a charitable grant to Sozialhelden, to fund the technical integration of data concerning the functionality of elevators in order to display the operational status of more than 2,700 elevators across Germany.

In order to ensure that the project could grow successfully and have an impact, Wheelmap’s activity was designed for scalability from the beginning. Wheelmap is based largely on the free world map OpenStreetMap, which stores all the data. The data sets are then published under the Open Database License and are available to be used free of charge. The technical backend of Wheelmap.org is the online service Accessibility.cloud, another initiative by Sozialhelden, one which contains another dataset, provided by partners with different licenses and incorporated into the map. The Wheelmap project has won various national and international prizes, such as World Summit Award Mobile in 2012 by United Nations and Vodafone Accessibility Award in 2011. In 2019 the Wheelmap team launched a new project called TravelAble, using the data and experience to create another app that also relies on the local knowledge of users to make accessibility information available.

An empowering wearable biosensor designed to detect vaginal infections.



Vaginal infections represent a significant health burden on women and, due to their recurrence, often bring loss of confidence and distress, with negative consequences on quality of life. Furthermore, societal stigma around these conditions prevents the normalization of the discourse, putting women at risk of medical complications. The Alma project aims to develop a reusable, inexpensive, less invasive sensing platform for vaginal fluid analysis, one capable of detecting pH and lactic acid from vaginal secretions, and to gather data that can be stored and used to reconstruct an individual's physiological profile over an extended period of time.

Conditions such as candida vulvovaginitis and bacterial vaginosis are infections resulting from shifts in the microflora in which symbiotic, beneficial microbial species are overwhelmed by other commensal species, which, if left unchecked, lead to detrimental effects. The project is exploring how low-cost technological solutions can help measure the microflora while also empowering women to become more familiar with their own bodies, develop the confidence to open a dialogue with specialists, and discuss their symptoms openly,

breaking some of the taboos still attached to gynecological health. While currently in the prototype stage, the project's documentation has been released online by the multidisciplinary team of creators led by Giulia Tomasello, a designer focusing on women's healthcare, together with Tommaso Busolo, James Che and Michele Calabrese, all from the University of Cambridge.



Alma's sensors are embedded in the folds of women's underwear and connected to a flexible circuit board, creating a fully integrated device designed for prolonged use. While the array of sensors has a limited lifetime as the enzymes in the lactate sensor tend to degrade, it has been designed to be easily removable and replaceable, reducing waste and cost. In fact, while previous models used photolithography, which is expensive and complex, the main improvement in Alma's approach is to fabricate the electrode and conductive paths using aerosol jet printing. This method has been proven to be cheaper, quicker and more easily adaptable to different design requirements.

Alma won the Biomaker Spirit Award at the Cambridge Biomaker Challenge 2018 and Giulia Tomasello won Ars Electronica's STARTS Grand Prize for Artistic Exploration with her other project Future Flora. The team at Alma also built a user-friendly mobile app designed to provide an interface for the sensor sampling the fluid pH at regular intervals, and to send information via Bluetooth to the user's smartphone.

A Visual Guide for Makers.

An introduction to the regulations to design, commercialize and distribute an open source medical device in the EU

OPEN SOURCE MEDICAL DEVICES

A VISUAL GUIDE FOR MAKERS

An introduction to the regulations to design, commercialize and distribute an open source medical device in EU

STEP ONE

UNDERSTAND WHAT YOU ARE RELEASING

Are you developing a hardware device or a digital fabricated solution to solve a challenge in the field of health and care? Not all the solutions need to be certified as medical devices. Identify which scenario your solution belongs to.

SCENARIO A

Your solution is a functioning DIY prototype. People can access the documentation to potentially produce and use it for themselves, to test, improve or study it.

SCENARIO B

Your solution can be personalized and produced in a fablab or a makerspace to support real people's needs.

SCENARIO C

Your solution is a hack of an existing object or medical device.

SCENARIO D

You are self-producing a solution for one person, or a few people, who will get it directly from you to use it in their daily life.

SCENARIO E

Your solution can be potentially mass produced or manufactured in small scale, and distributed by a third party, like a non profit organization, a tech for good company or by your future social enterprise.

YOU PROJECT NEEDS THE CERTIFICATION

WHAT SHOULD YOU DO?

Document the solution clearly and do not forget to add some information regarding what it should be improved to make it more stable.

SEE EXAMPLES ON CAREABLES.ORG

Do not forget to add information about the safety and the results of testing sessions into the documentation. Make people aware about possible risks when using the solution.

SEE INITIATIVE HACKABILITY.IT

Make people aware that the hacked version of a medical device is not suitable for all.

You are responsible for your designs. Reflect on how to avoid risks for the people.








Be sure that the requirements for the EU regulation compliance are considered in the design and development process of your solution.

GO TO STEP TWO

STEP TWO

UNDERSTAND THE MEDICAL PURPOSE

To start the certification procedure you should identify what category your medical device belongs to. Look at the following medical purposes to work out what type of medical device you are working with.

TYPE	PREVENTION	DIAGNOSIS	MONITORING	PREDICTION	TREATMENT	COMPENSATION FOR	PROVIDING INFO WITH ANALYSIS
DEFINITION	The act of stopping something from happening.	A judgment about what a particular illness or problem is, made after examination.	To watch and check a situation carefully for a period of time in order to discover something.	A statement about what it will or might happen in the future.	Medical care given to a patient for an illness or injury.	To make something bad less severe, such as pain or problems.	In vitro analysis of specimens derived from the human body
EXAMPLE	 Device for breast self-examination	 Low cost echo-stethoscope	 Intelligent monitoring device for Parkinson's	 Low cost sensors for early disease detection	 Pad for growing bacteria and cure vaginal infections	 DIY stoma bag	 Open source machine (PCR) to make copies of DNA segments

STEP THREE

IDENTIFY THE CLASS OF RISK

Medical devices are rated by their potential risk of use. The EU has 22 rules which will allow you to classify your project in the official Classes of Risks. Most maker projects are low risk. Explore the rules to work out what Class of Risk your project fits into.

RULES

NON INVASIVE
(Rule 1-4)

INVASIVE
(Rule 5)

ACTIVE
(Rule 9-13)

SPECIAL
(Rule 14-22)

CLASSES OF RISK

CLASS I
Low risk

CLASS IIA
Moderate Risk

CLASS IIB
Medium to High Risk

CLASS III
High risk



EXAMPLE

YOUR PROJECT IS
A SPORT WHEELCHAIR

It is not invasive because it does not touch orifices or emit radiations.

It is not invasive because it touches only intact skin.

It is not active because it is not electrified.

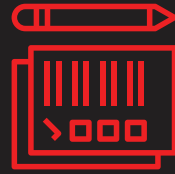
YOU PROJECT BELONGS TO CLASS I

Use the free Decision tree on UBORA platform to identify the Risk Class of your Medical Device: <https://platform.ubora-biomedical.org>

STEP FOUR

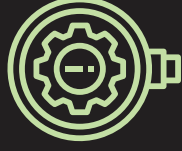
DETERMINE THE ASSESSMENT PROCEDURE

Medical device manufacturers have to follow conformity assessment procedures before placing products on the market. The type of conformity assessment procedure depends on the Class of Risk your project fits into.



ANY RISK FOUND?

If your device belongs to Class of Risk II or III, a Notifying Body must inspect and control your device.



If your device is low-risk and classified in CLASS I you can start a self-assessment procedure and check the compliance with the general safety requirements and harmonised standards.

Read all 23 Requirements on Annex I at this link bit.ly/EURegulationsMedicalDevices

LET'S DO AN EXERCISE TO ASSESS THE GENERAL SAFETY AND QUALITY OF YOUR DEVICE

RISK MANAGEMENT

Are you aware of all risks that your device can cause? Can you anticipate them? Can you find a solution to them?



DESIGN AND MANUFACTURE

What materials are you using? Are they potentially harmful? What are the physical properties of your device? Is it stable enough?



INFORMATION

Does your device need instructions to be used? Is all information stated clearly?



WHAT IF

YOU DEVELOPED A CUSTOM MEDICAL DEVICE

A custom medical device is a device that is prescribed by a doctor to a patient. If you made a custom orthosis with a 3D printer that fits one person's need, this does not mean that your orthosis is a custom medical device according to the EU regulations.

"Custom-made device" means any device specifically made in accordance with a written prescription of any person authorised by national law by virtue of this person's professional qualifications which gives, under his responsibility, specific design characteristics, and is intended for the sole use of a particular patient exclusively to meet their individual conditions and needs." MDR 2017/745 Article 2 (3)



ARE YOU HACKING?
A hacked version of an existing device is not a custom device.
See Scenario 3 In STEP ONE

EXAMPLES

A doctor uses your lab and equipment to commission a custom insole. You are making a custom medical device Class I, but you do not need a certification.



Open Bionics prosthetics hand

You made a custom 3D printed hand that is attached to a support. You need to certify only the universal support.



Universal Socket Prosthetic

A doctor uses your lab and equipment to commission a custom insole. You are making a custom medical device Class I, but you do not need a certification.



Gyrobot Limited 3D printed insole

WHAT IF YOU DEVELOPED A SOFTWARE

Your software connects to a medical device

Your software allows the user to read and visualise data from a glucose sensor through the sensor's official APIs.

YOU DON'T NEED THE CERTIFICATION



Glimp is an app to remotely share glycemia data from certified sensors and does not need a certification.

Your software is standalone and works as a medical device

Your software suggests a therapy according to the level of insulin. It means that the software is suggesting a cure and it is then a medical software.

YOU NEED THE CERTIFICATION

Software with a medical purpose can also be considered a medical device and belong to different Classes of Risks. Discover your options.

See the regulations for classifying the standalone software mdr 2017/745, Chapter I, Article 2 (4)

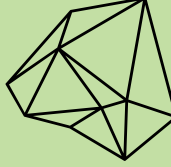
CREDITS AND RESOURCES

This guide is based on the webinar Open Source Medical Device held by Carmelo De Maria and Licia di Pietro on 6th February 2019 within the series Digital Social Innovation webinars by WeMake - DSIScale/DSI4EU.

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www.wemake.cc



www.digitalsocial.eu



ubora-biomedical.org

LIST OF PROJECTS AND REFERENCES

- Careables Open Source Hardware in health care
www.careables.com
- Hackability Methodological hackathon to co-design supports
www.hackability.it
- Palpreast Wearable Device for Breast Self- Examination
<https://bit.ly/2QCNqGN>
- Echopen open source and low-cost echo- stethoscope
www.echopen.org
- OneRing Intelligent Monitoring Device for Parkinsons
<https://bit.ly/2XkgXYC>
- E-Health: Low Cost Sensors for Early Disease Detection
<https://bit.ly/2ELP7wX>
- Insoles Generate Insoles for 3D Printing
www.gensole.com
- Glimp App to sharing glycemia data
<https://bit.ly/2EJUrkg>
- E-Health: Low Cost Sensors for Early Disease Detection
<https://bit.ly/2ELP7wX>
- Future Flora Kit to treat and prevent vaginal infections
www.gitomasello.com/Future-Flora
- Stomanoir Cap for stoma bags
<https://bit.ly/2EL7fap>
- Open PCR Open-source PCR Thermocycler
www.openpcr.org
- OpenBionics Open-source Robotic & Bionic Hands
www.openbionics.org
- Toowheels Open-source sport wheelchair
www.toowheels.org/
- Universal Socket Prosthetics
www.thingiverse.com/thing:2718065
- DSI Webinars - Learning Journey Playlist
<https://bit.ly/2wr5WZF>

"Open Medical Devices - A visual guide for makers" is included in e-book "Rebelling with care" available at this link
<http://wemake.cc/digitalsocial/cure-ribelli/>



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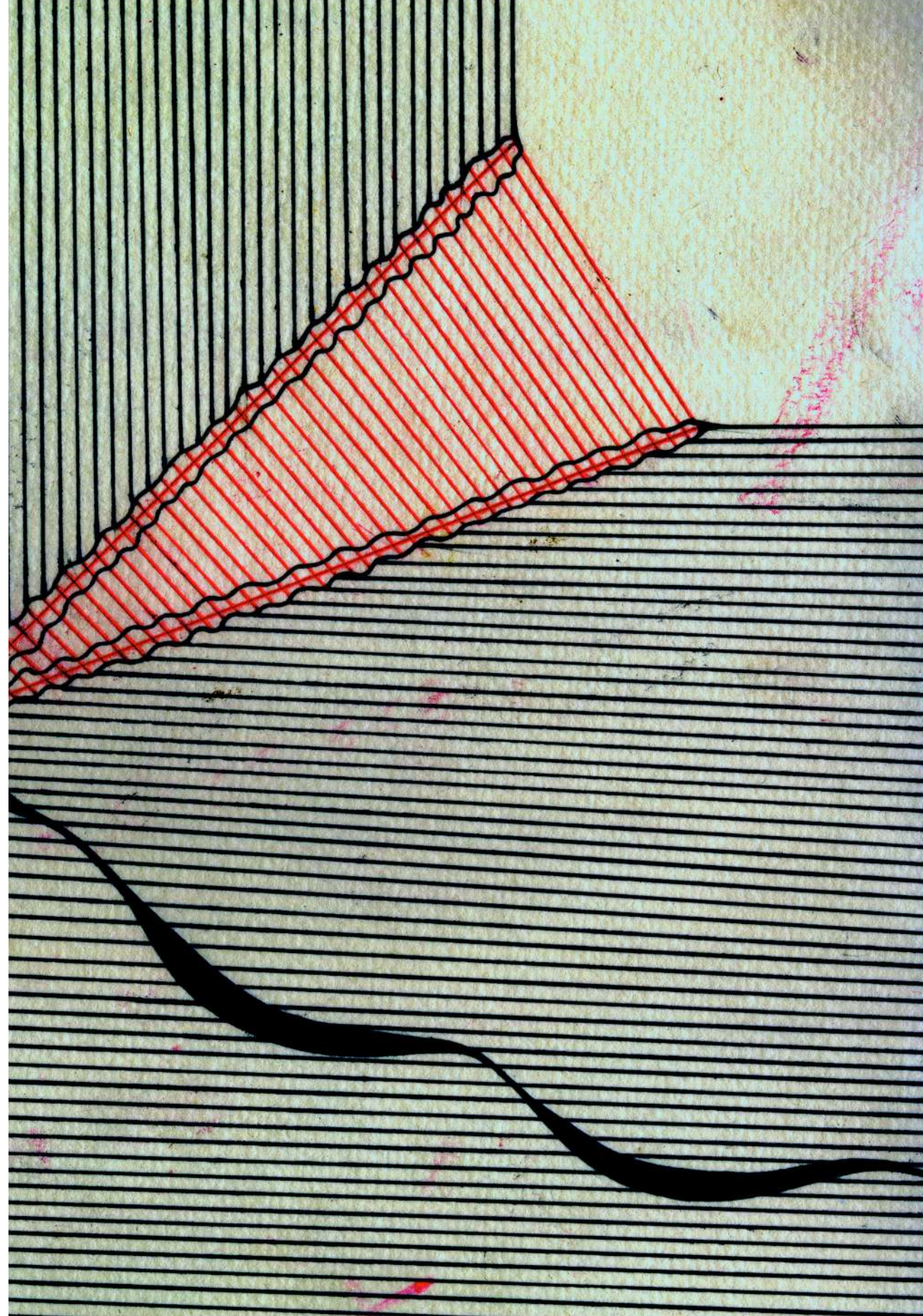
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As Digital Social Innovation has become more widely used in practice and in theory, and if its impact is to grow as we would like it to, we must become clearer about the meanings of the concepts it represents. Language is not just expressing what we see and what has to be done, but rather is a tool we all use to imagine and build the world we want to see.



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